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CONCISE REPORT

Practice patterns in longitudinal lupus care provision: patient and physician perspectives

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Background/purpose: To plan a quality improvement project, we need to understand the practice patterns of physicians. We undertook an online survey of systemic lupus erythematosus (SLE) patients and physicians providing care to SLE patients to determine the patterns of medical care provided to SLE patients. **Materials and methods:** Two self-report surveys were developed. A 12-item survey for the patients and a 13-item survey for physicians enquired about longitudinal care for SLE. Surveys were administered online to physicians providing care to SLE patients, and to patients who self-identified as having SLE, through the Lupus Society of Illinois. Patient and physician data were analyzed for physician practice patterns for SLE care, using chi square tests and *t* tests. A *P* value of 0.05 or less was considered significant on two-tailed tests. **Results:** A total of 283 patients completed the survey. Mean (SD) age and disease duration of patients were 45.9 (13.2) and 12.7 (9.7) years. Half of the participants were being seen at 3–4-month intervals. More than 70% of patients reported being tested for antinuclear antibody (ANA), and 20–30% anti-ENA antibody and Sjögren's (SSA/SSB) antibodies, respectively, at each follow-up visit. Eighty-six rheumatologists completed the surveys. Mean (SD) age was 55 (12) years and 56% were men. More than half (54%) provided care only in a private practice setting. More than 80% of physicians reported seeing their SLE patients at 3–4-month interval. Only 2% reported performing ANA tests at each visit, while 4–5% performed anti-ENA and anti-SSA/SSB antibody tests at each visit for their SLE patients. More than 75% of physicians in private practice also ordered sedimentation rate at each visit for their SLE patients. **Conclusions:** Unnecessary laboratory investigations may be being ordered routinely for patients at every visit. These results indicate a need for physician education on indications and utility of some of the laboratory tests such as ANA. *Lupus* (2017) **0,** 1–6.

Key words: Systemic lupus erythematosus; physician practices; practice variation

Introduction

Unwarranted variation in medical care delivery refers to differences in medical care delivery that cannot be explained by illness, medical need or the principles of evidence-based medicine. It can be caused by shortfalls in three areas: (a) effective care and patient safety; (b) preference sensitive care; and (c) supply sensitive care. Of these three, supply sensitive care is dependent on the resources of the healthcare system and is usually provided in the absence of good medical evidence. In the USA, easy access to laboratory tests for insured systemic lupus erythematosus (SLE) patients may potentially allow for non-evidence-based practice patterns, increase in healthcare cost burden, without necessarily improving outcomes.

SLE, an autoimmune disease, is marked by periods of flares and significantly impairs patients' quality of life (QOL). A cumulative effect on QOL in SLE may exceed that of some of the common chronic diseases.[1] Rashes, fatigue and joint pain are some of the common perceptible symptoms that lead SLE patients to seek medical care; onset of internal manifestations (such as cytopenia, nephritis) may not be easily perceptible to patients. These clinically silent manifestations can be detected early and monitored with blood tests such as complete blood count and urinalysis. Laboratory tests are also required to monitor side effects of the immunosuppressive medications in

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SLE. Early diagnosis of disease activity in organs is key to prevent and/or limit irreversible damage, by timely institution of an appropriate treatment plan. Furthermore, evidence of improvement/resolution of ongoing disease activity may result in de-escalation of the treatment regimen to limit/prevent unwarranted medication side effects. Thus SLE patients require careful and long-term follow-up, including laboratory tests, with their care providers.

Healthcare costs associated with SLE can be substantial. The average annual direct medical cost was Canadian $10,608 and was higher for patients with severe disease ($15,048 vs. $5,917, $P < 0.001$).[2] In the Medicaid database, the estimated incremental annual cost associated with SLE was US $10,984 when compared to age-matched controls.[3] Cost per flare correlated with the severity of the flare ($11,716 for severe, $562 for moderate, $129 for mild). Annual total costs for SLE patients with severe flares were $49,754.[3] Indirect costs for SLE are also substantial, causing significant burden on patients and their families.[4] Physician practice variations may influence healthcare utilization, healthcare cost and outcomes.[5,6] Understanding physician practice patterns may provide insight into potential opportunities for decreasing unnecessary healthcare costs. We conducted a survey study to understand better physician practice variations in longitudinal care received by SLE patients from both the recipient and the care provider viewpoint.

Materials and methods

We chose survey study methodology to obtain: (a) a large and heterogeneous group of community-based SLE patients and physicians (providing care to SLE patients) for better generalizability; and (b) access to data in a time and resource-efficient manner. We partnered with the Lupus Society of Illinois (LSI) for recruitment. For the SLE patient survey study, a 12-item patient survey (Supplementary Appendix 1) was designed using item development guidelines. Survey reading level of sixth grade was ensured.[7] Each question had multiple choice answers. A covering letter explaining the study purpose was posted on LSI social media (Facebook, blog, Twitter). Patients with self-reported SLE history, who agreed to participate voluntarily, used a web link to access the survey. Before starting the study, the patients were asked in the survey if they had SLE. The condition was fully spelt out along with a brief simple descriptor distinguishing it from cutaneous lupus alone. If the respondents answered 'yes', only then were they able to proceed further. Since the patients were on the listing of the LSI, we presumed a high likelihood of accurate reporting of their known diagnosis of SLE. Patients were instructed to refer to their healthcare records, receipts and discharge notes from their physician outpatient visits to answer questions on healthcare cost.

A 13-item physician survey (Supplementary Appendix 2) was designed for the physician providers of SLE patients. It was e-mailed with a cover letter to the physicians providing longitudinal care to SLE patients nationwide. Physicians who responded to the survey included rheumatologists, nephrologists and primary care physicians.

The institutional review board (IRB) at Rush University approved this project. Patients and physicians were recruited for voluntary participation in this online survey based through posting on social media of LSI or electronic mails to physicians. The need for written consent for the participation and publication was waived by the IRB because of the non-invasive nature of the study and minimal risk to loss of confidentiality of participants. No participant identifiers were used in either survey.

Statistics

Analyses were performed using SPSS, version 17. Descriptives were obtained for each group of respondents. The t test and chi square tests were performed within each group to test for correlates of practice patterns. A P value of 0.05 or less was considered significant on two-tailed tests.

Results

Physician survey study results

A total of 86 physicians completed the survey; most (97%) were rheumatologists. Eighty-six per cent of physicians were non-Illinois physicians. Of these 86 physicians, 46 practised in an academic setting, 27 in private practice, and the remainder in both. The mean (SD) age of physicians was 55 (12) years (Table 1). Ninety per cent of physicians reported being currently board certified in their field. Sixty-four per cent were over 15 years out of medical training (Table 1). More than 60% of physicians worked over 20 hours per week and more than half of them encountered more than 20 SLE patients in the clinic monthly. The

majority (81%) reported seeing their SLE patients every 3–4 months. Seventy-two per cent of physicians performed an immunofluorescence assay (IFA) for an ANA test compared to ELISA (72% vs. 28%, $P = 0.01$). Only 2% reported performing an ANA test routinely at each follow-up visit for their SLE patients. ENA and SSA/SSB antibodies were checked routinely at each visit by 5% and 4% of physician, respectively. Seventy-seven per cent of physicians ordered dsDNA, and 82% C3/C4 at each visit. Urinalysis was ordered for 92% of SLE patients at each visit routinely. Forty-three per cent and almost 69% ordered CRP and/or ESR, respectively, at each visit. Specific tests ordered routinely are noted in Table 1.

Stratified analysis by work setting type

No significant differences were noted between academic and private practice physicians based on demographics, training or medical certification status; however, work hours per week was higher among private practitioners (>20 hours/week 96% vs. 46%, $P < 0.001$). No significant differences were noted in the number of SLE patients seen monthly or the period between their longitudinal patient care visits based on physician work setting. Several significant differences were noted among physicians based on their work setting type regarding the following: (a) laboratory test methodology preference for ANA; (b) laboratory tests ordered longitudinally at each follow-up visit

Table 1 Physician Survey Results

Variable	*All MD's*	*Academic*	*Private*	*P value*
N	86	46(54%)	27(32%)	
Age (mean± SD) years	55±12	56.1 (11.5)	51.7 (11.8)	0.13
Male (%)	56%	24(52%)	15(56%)	0.78
Currently Board Certified (%)	90%	41 (89%)	26 (96%)	0.4
Rheumatologist (%)	97%	45(98%)	27(100%)	1
Years out of training in years (%)				
0 to 5	11%	3(7%)	4(15%)	0.56
6 to 10	13%	6(12%)	5(19%)	
11 to 15	12%	5(11%)	3(11%)	
>15	64%	32(70%)	15(55%)	
Practice setting (%)				
Academic	32%			
Private practice	54%			
Both	14%			
Foreign medical graduates (%)	35%	13 (28%)	10(37%)	0.44
Number of hours/week worked				
<10	8%	6(13%)	1(4%)	<0.001
11 to 20	26%	19(41%)	0(0%)	
>20	66%	21(46%)	26(96%)	
Number of SLE patients seen/month				
<10	15%	6(13%)	5(19%)	0.72
11 to 20	29%	12(26%)	8(30%)	
>20	55%	28(61%)	14(50%)	
Average period between SLE visits (%)				
1 to 2 months	12%	7(15%)	2(7%)	0.52
3 to 4 months	82%	36(78%)	24(89%)	
5-6 months	6%	3(7%)	1(4%)	
ANA testing method (%)				
ELISA	28%	8(17%)	12(44%)	0.01
IFA	72%	38(83%)	15(56%)	
Tests ordered at each SLE visit (%)				
ANA	2%	0(0)%	2(7%)	0.13
Anti dS-DNA	77%	32(70%)	25(93%)	0.04
Anti ENA	5%	0(0)%	3(11%)	0.05
Anti SSA/SSB	4%	0(0)%	3(11%)	0.05
C3/C4	83%	40(87%)	21(78%)	0.31
ESR	59%	21(46%)	21(78%)	0.007
C Reactive protein	43%	12(26%)	19(70%)	<0.001
Urinalysis	92%	43(94%)	25(93%)	1
Urine protein/creatinine	36%	20(44%)	8(30%)	0.24
24 hours urine for protein	4%	1(2%)	2(7%)	0.28

Table 2 Patient reported survey results

Mean Age (standard Deviation) in years	45.9(13.2)
Women	93%
Illinois resident	77%
Disease duration	12.7(9.7)
SLE- Kidney Disease	38%
Doctor type	
Rheumatologist only	74%
Nephrologist	2%
Both	24%
Care setting	
Private practice	47%
Teaching	27%
Both	26%
Interval between visits	
1-2 months	23%
3-6 months	50%
5-6 months	18%
Annually	9%
Tests ordered by Rheumatologist at each visit	
ANA	70%
Ds-DNA	44%
ENA (RNP/Sm)	22%
SS-A/SS-B	27%
C3/c4	60%
ESR	52%
CRP	68%
UA	66%
UPC	64%
24 hour urine protein	10%
Billing per visit (USD)	
<100	27%
101–200	24%
201–300	18%
>300	31%

(Table 1). Physicians in private practice used the ELISA method more commonly than IFA for ANA testing when compared to academic setting physicians (44% vs. 17%, $P = 0.01$). All physicians ordering ANA, ENA and SSA/SSB at each follow-up visit worked in a private practice setting (Table 1). Also, private practice physicians ordered ESR and CRP more frequently at each visit compared to those in an academic setting (ESR 78% vs. 46%, $P = 0.007$ and CRP 70% vs. 26%, $P < 0.001$).

Patient survey study

A total of 283 respondents with a self-reported diagnosis of SLE completed the surveys. The mean (SD) age and disease duration of SLE patients were 45.9 (13.2) years and 12.7 (9.7) years, respectively (Table 2). More than 75% of respondents were from Illinois. The majority (93%) were women. Of the 283 patients, 74% were receiving care from a rheumatologist only. More than half of the doctor visits were in a private practice setting ($P = 0.007$). For over half of the patients their SLE visits were routinely 3–4 months apart, and for 23% at 1–2-monthly intervals. Average expenditure for the blood/urine test at each routine visit exceeded $300 for 31% of patients. Expenditure between $201–300, $101–200 and $100 or less was reported by 18%, 24% and 27% of patients, respectively. Over 70% of patients reported being tested for ANA and CRP at each visit (Table 2), while 53% were tested for ESR at each visit (Figure 1). For other tests ordered

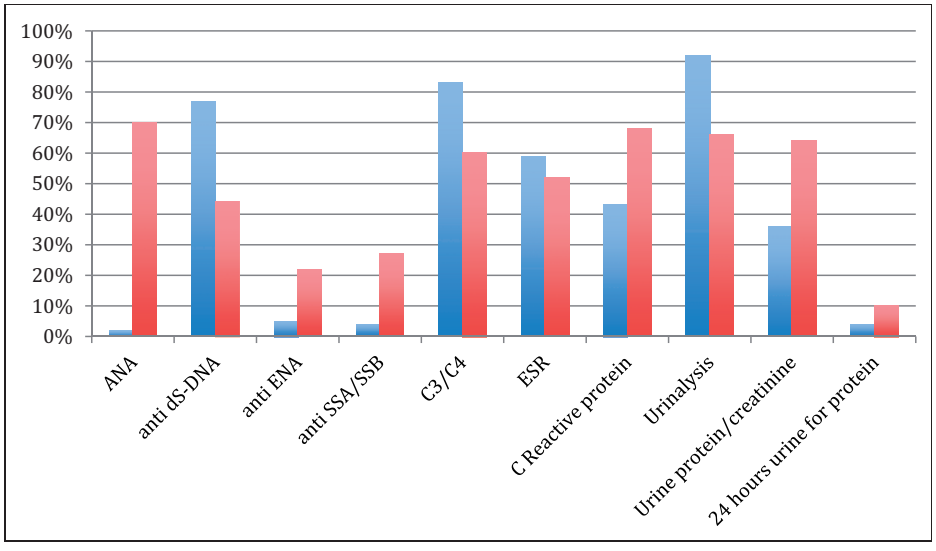

Figure 1 Percentage of laboratory tests ordered by physicians at each patient care visit as reported by patients (red) and physicians (blue).

at each visit routinely, see Table 1. SLE-related renal disease was reported by 38%: Of these, 58% were followed with both a rheumatologist and nephrologist, while 39% were followed with only a rheumatologist ($P = 0.0001$).

Patient data stratified by SLE renal disease

Complements were more often ordered among patients with SLE renal disease diagnosis (69% vs. 55%, $P = 0.013$). The urine protein creatinine ratio was ordered more often for SLE renal disease patients (79% vs. 55%, $P = 0.001$) than for those without.

Discussion

Studies of physician practice variations provide an important insight into healthcare utilization across groups. Variations are driven by multiple factors. Some physician variations are to be expected, especially in patients with chronic disease such as SLE, as the disease is heterogeneous in its manifestations. The medical management selected may be based on: (a) patients' age and gender-specific concerns; (b) logistics of cost, insurance and tolerance to medications; or (c) patient preference. Variations are considered unwarranted when they cannot be explained with reference to patient preference, condition or evidence-based medicine.[8]

The study was undertaken to learn about physician practice patterns in SLE, from the viewpoint of both the consumer and the provider. Seventy per cent of patients reported testing for ANA at each visit. However, physicians reported performing ANA (2%), anti-ENA (5%) and anti-SSA/SSB (4%) serially at each visit. All of these physicians were in a private practice setting. This discrepancy can be expected due to the potential for social desirability bias among physicians, resulting in underreporting and underestimation. Most SLE patients are familiar with the ANA test; however, patient reporting may be limited by recall bias. To reduce recall bias, we had instructed patients to refer to their medical records, laboratory test reports and billing records to identify the tests routinely ordered for their SLE at each visit, and the cost incurred. Serial testing of ANA, anti-ENA, anti-SSA/SSB in patients' longitudinal management is not evidence based. Although the physician-reported prevalence of serial ANA, anti-ENA, anti-SSA/SSB was relatively low, it would be considered an unwarranted physician practice variation in the management of SLE. Our study supports the use of medical claims data to study these issues further.

Unwarranted variations influence healthcare utilization, without improving health outcomes. The identification of inefficiencies in healthcare provision and their source can help reduce healthcare cost and standardize care.[9] The development and dissemination of 'best practices guidelines' regarding 'laboratory testing of various autoantibodies' longitudinally in SLE management is indicated.

There are limitations to our study. First, the inclusion criterion for patients was a self-reported diagnosis of SLE, which may have led to the inclusion of cutaneous lupus erythematosus (without SLE) or SLE patients not meeting American College of Rheumatology classification criteria. No patient or provider identifiers were used to prevent reporting bias. This limited our ability to verify SLE diagnosis with their providers. Physician sample size was relatively small. However, respondent physicians represented a national sample of varied physicians and practice settings. Most of our patients were from Illinois limiting the generalizability. There are recall, selection and reporting biases inherent in the self-reported survey design. However, physician reporting bias may have led to underestimation of the magnitude of unwarranted variations in laboratory testing in SLE care. Patients may overestimate the cost or the number of tests ordered routinely at each visit.

Conclusions

Our study indicates potential unwarranted physician practice variations in laboratory evaluations ordered routinely at each visit during SLE care. A systematic study of the prevalent practice patterns in SLE, using a non-survey methodology, to confirm the findings and identify potential areas of improvement is suggested. Evidence-based guidelines on the utility of serial testing for specific autoantibodies in the management of SLE need to be developed and disseminated to physicians.

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Author contributions

Meenakshi Jolly was the main contributor for the conception, design, analysis and interpretation of data. Mary Dollear was involved in the distribution and gathering of the survey to the patients and physicians via LSI. Aman Kugasia was involved in drafting the manuscript and revising it critically for important intellectual content. Neha Sehgal was the associated scriptwriter assisting Aman Kugasia. Winston Sequiera, Joel Block and Dr Nika gave their expert comments on the drafted manuscript and gave final approval to the version to be published. All authors read and approval the final manuscript.

Declaration of conflicting interests

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