Clinical Research in SLE

618 OUTCOMES OF PEDIATRIC LUPUS CARE DELIVERY IN AN ELECTRONIC HEALTH RECORD-BASED PEDIATRIC LUPUS REGISTRY

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Background There is a need to identify strategies to improve outcomes of children with pediatric-onset systemic lupus erythematosus (pSLE) and related conditions. Current data collection methods commonly employed for research and quality improvement efforts are labor intensive and frequently unsustainable. We describe the use of an autopopulating EHR-based pSLE registry to measure outcomes before and after a Maintenance of Certification (MOC) activity to improve high-quality care delivery.

Methods

Data source We extracted data from our EHR-based pSLE research registry from Dec 2018 – July 2022. In November 2018, we implemented electronic health record (EHR) tools at our center to standardize documentation of pSLE clinical characteristics, medication instructions, disease activity, disease damage and target assessments, which autopopulate a quality improvement dashboard and the pSLE research registry. The research registry additionally interfaces with an EHR-based steroid registry and billing data on hospital and rheumatology visit encounters in real-time.

Setting Coinciding with the development of EHR-based tools for pSLE, our center established a Lupus Program in 2018 with input from providers, foundation leaders, patients and families. As of May 2019, programmatic components included a dedicated lupus social worker and a multidisciplinary lupus nephritis clinic with social work support and a psychologist. In order to ensure delivery of high quality care across rheumatology, we began an MOC activity in July 2020 to improve performance on metrics in the previously published pediatric Lupus Care Index (pLUCI). Components included a population management strategy, self-directed evaluation for individual providers, and goal-setting activities.

Measures Primary outcomes included timely follow-up care (defined as <120 days between clinic visits), pneumococcal vaccination rates, and use of steroid-sparing agents. We used modified (robust) Poisson models to estimate the relative probability of each outcome before and after the MOC activity, adjusted for time, patient-level factors (sex, race and ethnicity, social vulnerability index [SVI], major organ manifestations), visit-level factors (age, disease duration, disease activity, prednisone use, and DMARD use), as well as within-subject random effects.

Results Of 133 pSLE or mixed connective tissue disease cases in the EHR-based Registry, 128 had both patient- level and visit-level data forms entered by providers. 110 of these patients had at least two outpatient rheumatology visits during the observation period and were included in this study, 74 of which had follow-up that extended through both pre- and post-MOC periods. There was a median of 7 visits per subject [4-10], comprising a total of 830 outpatient rheumatology

Abstract 618 Table 1 Baseline Characteristics at index visit before and after start of MOC

	Pre-MOC N = 88	Post-MOC N = 96	p-value
Age at SLE diagnosis (y), mean (SD)	13.4 (3.5)	13.4 (3.4)	0.85
Age at index visit	16.3 (3.1)	16.6 (3.4)	0.47
Disease duration (y), median [IQR]	1.8 [0.3-4.7]	2.6 [0.3-4.8]	0.34
Female sex, n (%)	69 (79%)	79 (82%)	0.61
Race			
Asian	17 (20%)	19 (20%)	0.76
Black	34 (39%)	37 (39%)	
Other	10 (11%)	15 (16%)	
White	26 (30%)	24 (25%)	
Unknown	0 (0%)	1 (1%)	
Hispanic ethnicity	10 (11%)	12 (13%)	0.83
Insurance			
Medicaid	45 (52%)	50 (52%)	0.37
Private	40 (46%)	45 (47%)	
Self-Pay/Other	2 (2%)	1 (1%)	
Social Vulnerability Index			
Lowest	22 (25%)	29 (30%)	0.79
Medium Low	19 (22%)	19 (20%)	
Medium High	23 (26%)	23 (24%)	
Highest	23 (26%)	25 (26%)	
Clinic setting			
Rheumatology	82 (93%)	84 (88%)	0.19
Multidisciplinary	6 (7%)	12 (13%)	
Historical Lupus Manifestations			
Acute cutaneous	32 (37%)	36 (38%)	0.83
Chronic cutaneous	12 (14%)	11 (12%)	0.67
Mucocutaneous ulcers	22 (25%)	24 (26%)	0.97
Arthritis	43 (49%)	48 (51%)	0.77
Serositis	7 (8%)	8 (9%)	0.93
Nephritis	29 (33%)	30 (32%)	0.84
Neuropsychiatric	5 (6%)	5 (5%)	0.93
Hemolytic anemia	17 (19%)	19 (20%)	0.85
Leukopenia	40 (46%)	42 (46%)	0.97
Thrombocytopenia	17 (20%)	17 (18%)	0.83
ANA positive	87 (99%)	94 (99%)	0.96
dsDNA antibody positive	65 (74%)	70 (76%)	0.73
Antiphospholipid antibody positive	32 (37%)	34 (37%)	0.94
Hypocomplementemia	59 (68%)	67 (73%)	0.46
Lupus Treatments (Ever Use)			
Cyclophosphamide	14 (16%)	13 (14%)	0.65
Mycophenolate	63 (72%)	70 (73%)	0.84
Azathioprine	8 (9%)	9 (9%)	0.95
Methotrexate	31 (35%)	32 (33%)	0.79
Calcineurin inhibitor	4 (5%)	5 (5%)	0.84
Hydroxychloroquine	86 (98%)	95 (99%)	0.51
Rituximab	30 (34%)	29 (30%)	0.57
Belimumab	5 (6%)	6 (6%)	0.87
Disease Status and Treatment at Index Visit (Current Use)			
SLEDAI, median [IQR]	0 [0-4]	0 [0-4]	0.96
Any DMARD use*	55 (93%)	51 (88%)	0.33
Prednisone use	40 (58%)	30 (42%)	0.05
Prednisone dose among users (mg/day), median [IQR]	10 [10-30]	10 [5-30]	0.60

Demographic and clinical characteristics at the index visit for each subject, defined as the first visit occurring in each period (pre-MOC = December 2018 – June 2020; post-MOC = July 2020 – July 2022)

* Includes mycophenolate, azathioprine, methotrexate, calcineurin inhibitors, sirolimus, belimumab

visits. Demographic and clinical characteristics at the index visit in both pre- and post-MOC periods are shown in table 1.

The standardized EHR documentation tool was used in 79% of visits pre-MOC and 87% of visits after MOC activities. Both SLEDAI scores and medication data were captured from 76% of pre-MOC visits and 80% of visits after MOC. There was no statistically significant difference in the probability of timely follow-up post-MOC vs. pre-MOC in adjusted models (65% vs. 59%, adjusted RR 1.09, 95% CI [0.93-1.28]). Hispanic ethnicity, shorter disease duration, higher disease activity, and any DMARD use at the preceding visit were associated with a higher likelihood of timely follow-up (table 2). Of note, Black race and higher SVI were not associated with a lower likelihood of timely follow-up during the observation period, which spanned introduction of a dedicated social worker, the multidisciplinary lupus nephritis clinic, and the COVID-19 pandemic. Among 35 patients with lupus nephritis, Asian race, Black race, Hispanic ethnicity, and higher SVI were all associated with a higher likelihood of timely follow-up. Timely follow-up was achieved 73% of the time in the 20 nephritis patients followed in the multidisciplinary clinic vs. 63% in 15 lupus nephritis patients followed in regular rheumatology clinic, albeit this difference did not reach statistical significance (adjusted RR 1.15 [0.88-1.50]).

On average, pneumococcal vaccination was high (up to date at 84% of visits) and increased over time during the observation period (adjusted RR 1.005 per month, [1.001 – 1.009]), but there was no significant difference pre- vs. post MOC. For lupus nephritis patients, pneumococcal vaccination status was up to date for 98% of visits in the multidisciplinary clinic compared to 90% of visits in rheumatology clinic, albeit not statistically significant (adjusted RR 1.09 [0.91 – 1.30]). There were no significant changes in use of a steroid-sparing agent over time or pre- vs. post MOC.

Abstract 618 Table 2 Factors associated with timely outpatient rheumatology follow-up

	RR	95% CI	p-value
Month of follow-up	0.99	[0.98 - 1.00]	0.09
Post-MOC	1.09	[0.93 - 1.28]	0.29
Age at visit	0.97	[0.94 – 1.00]	0.09
Male sex	0.92	[0.73 - 1.16]	0.49
Race/ethnicity			
Reference: Non-Hispanic White	-		
Asian alone or in combination	1.20	[0.91 - 1.58]	0.19
Black alone or in combination	1.22	[0.92 - 1.62]	0.17
Hispanic White/Other	1.51	[1.15 - 1.99]	0.00
Non-Hispanic Other race	0.54	[0.28 - 1.02]	0.06
Social Vulnerability Index			
Lowest			
Medium Low	1.00	[0.75 - 1.33]	0.98
Medium High	0.94	[0.71 - 1.25]	0.68
Highest	1.03	[0.82 - 1.29]	0.82
Within 6 months of diagnosis at last visit	1.26	[1.05 - 1.53]	0.02
Prednisone use at last visit	1.17	[0.93 - 1.46]	0.17
SLEDAI score at last visit	1.02	[1.01 - 1.04]	0.01
Any DMARD use at last visit	1.52	[1.04 - 2.24]	0.03
History of synovitis	0.85	[0.70 - 1.05]	0.13
History of lupus nephritis	1.13	[0.95 - 1.35]	0.17

Estimates from modified robust Poisson models with subject-level random effects

Conclusions Uptake of pSLE-specific EHR documentation tools was high in the context of a MOC activity to improve high quality pSLE care. While there was no significant change in timely follow-up associated with the MOC activity period, there were also no significant disparities by race or social vulnerability during the observation period, coinciding with a new multidisciplinary lupus program with dedicated social work and psychology support, as well as the COVID-19 pandemic. EHR-based pediatric lupus registries using standardized clinical documentation enables evaluation of longitudinal disease and care delivery outcomes without manual review of medical records and could facilitate learning health networks and health equity research.

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619 PROSPECTIVE EVALUATION OF ANTI-SSA/RO POSITIVE PREGNANCIES TO ADDRESS RISK FACTORS FOR FETAL CARDIAC DISEASE/ADVERSE PREGNANCY OUTCOMES AND EFFICACY OF AMBULATORY FETAL HEART RATE MONITORING (FHRM) AND RAPID TREATMENT OF EMERGENT BLOCK

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Introduction Fetal cardiac disease is strongly associated with maternal anti-SSA/Ro antibodies, but gaps in our knowledge include the influence of antibody specificity and titer, maternal diagnosis, overall non-cardiac adverse pregnancy outcomes (APOs), optimal surveillance protocols, and efficacy of rapid treatment.

Methods The multi-center **S**urveillance and **T**reatment **T**o **P**revent Fetal AV **B**lock **L**ikely to **O**ccur **Q**uickly (STOP BLOQ) study recruited pregnant women with commercially positive anti- Ro antibodies and stratified them into high and low titers of anti-Ro60 and Ro52 based on a research ELISA, using a cutoff defined by that obtained for 50 mothers with previous AVB offspring. Mothers with anti-Ro60 and/or 52 antibodies at or above 1,000 I.U. were trained to perform FHRM. From 17- 25 weeks of gestation, FHRM was completed 3x/day in addition to weekly or biweekly fetal echocardiograms (echo). Mothers texted all audio sounds to the coordinating center. Texts deemed abnormal by mothers were immediately sent to an on call pediatric cardiologist who