Assessing Barriers to Diagnosis Among Children with Pediatric Lupus

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BACKGROUND

- Children with Systemic Lupus Erythematous (SLE) often present with more advanced disease than adults, which may be partly due to delayed diagnosis and access to care.
- We aimed to determine what features of pediatric SLE (pSLE) might have been identified sooner, steps that providers took to investigate SLE, and define characteristics of patients diagnosed while inpatient compared to those diagnosed outpatient.

METHODS

Study Design – Retrospective chart review of 104 SLE patients seen at Seattle Children's Hospital since 2010.

Data collected – Patient demographics, pre- diagnosis course including labs obtained prior to rheumatology consultation and SLE diagnosis, alternative diagnoses, setting of diagnosis, and disease characteristics.

Statistical Analysis – Summary statistics were used to describe all children diagnosed with pSLE. Cross-sectional analyses of patients diagnosed in the inpatient versus outpatient settings were performed using Chi Square and Wilcoxon rank sum test.

PRELIMINARY RESULTS

Table 1: Patient characteristics (n=104)

Variables	Patient Characteristics
Sex	- Female = 81 (81%) - Male = 19 (19%)
Median [IQR] age at diagnosis	- Inpatient = 12.5 [11-15] - Outpatient = 14 [12-16]
Race or ethnicity	- Asian = 14 (14%) - Asian/White = 1 (1%) - Black or African American = 16 (16%) - Black or African American/White = 2 (2%) - Other = 25 (25%) - Patient Refused = 7 (7%) - Unknown = 10 (10%) - White = 25 (25%)
Insurance type	- Commercial = 36 (36%) - Medicaid = 50 (50%) - Medicare = 4 (4%) - Self-pay = 8 (8%) - Tricare = 1 (1%)
Primary language	- English = 88 (88%) - Spanish = 8 (8%) - Cambodian = 1 (1%) - Marshallese = 1 (1%) - Tagalog = 1 (1%) - Thai = 1 (1%)
Home state	- Washington = 93 (93%) - Montana = 2 (2%) - Alaska = 3 (3%) - Idaho = 1 (1%) - Wyoming = 1 (1%)

Figure 1: Laboratory tests ordered prior to rheumatology consult and SLE diagnosis (n = 104)

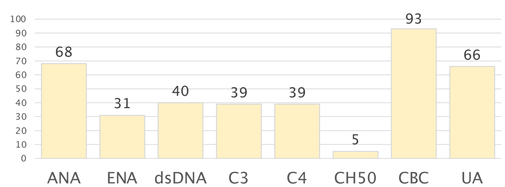

Figure 2: Alternative diagnoses to which symptoms were attributed prior to SLE diagnosis (n = 100)

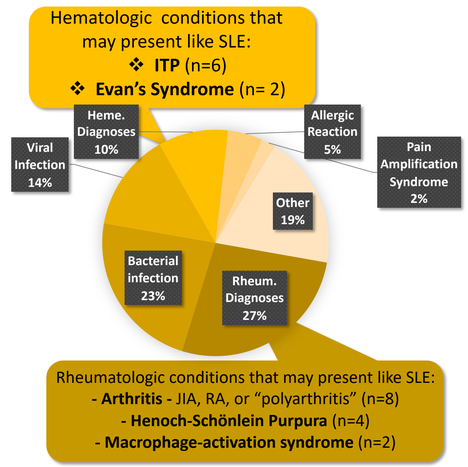

Figure 3: Percent of youth with symptoms at SLE diagnosis not included in 2019 ACR/EULAR or 1997 ACR diagnostic criteria (n=104)

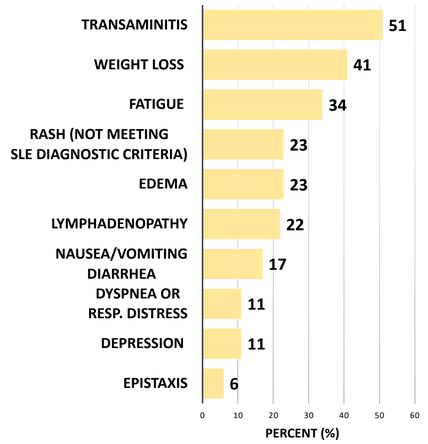

Table 2: Comparison of patient characteristics by diagnoses setting

Variable	Inpatient/Emergency Department (n=64)	Outpatient (n=38)	p-value
Nephritis within 2 weeks of diagnosis (n=47)	34 (72%)	13 (28%)	0.07
Race or ethnicity			0.2283
- Asian (n=13)	9 (69%)	4 (31%)	
- Asian/White (n=1)	1 (100%)	0 (0%)	
- Black or African American (n=16)	11 (69%)	5 (31%)	
- Black or African American/White (n=2)	1 (50%)	1 (50%)	
- Other (n=25)	18 (72%)	7 (28%)	
- Patient Refused (n= 7)	4 (57%)	3 (43%)	
- Unknown (n=10)	8 (80%)	2 (20%)	
- White (n=25)	10 (40%)	15 (60%)	
Insurance Type			0.10
- Commercial Insurance (n=36)	19 (53%)	17 (47%)	
- Medicaid (n=49)	34 (69%)	15 (31%)	
- Medicare (n=4)	4 (100%)	0 (0%)	
- Self-pay (n=8)	3 (37%)	5 (63%)	
- Tricare (n=1)	1 (100%)	0 (0%)	
Primary Language of			0.53
- English (n=87)	53 (61%)	34 (39%)	
- Non-English (n=12)	9 (75%)	3 (25%)	

DISCUSSION

- Non-rheumatologist providers most often ordered ANA, CBC, and UA prior to rheumatology consults.
  - Patients might benefit from earlier screening of tests more specific to SLE, such as anti-dsDNA, ENA, and complement levels.
- SLE can mimic other conditions. Common alternative diagnoses included UTIs (n=11), other arthritic conditions (n=8) and idiopathic thrombocytopenic purpura (n=6).
  - A limitation is a lack of data on whether these were conditions concurrent with SLE (ie, infection triggering flare), or misdiagnoses.
- Over twice as many patients on Medicaid were diagnosed in the inpatient setting (n=34) as outpatient (n=15), and all patients on Medicare were diagnosed while inpatient (n=4). Non-English speakers were diagnosed in the inpatient setting (n=9) three times more often than those outpatient (n=3). Whites were the only race/ethnic group to have a greater number of patients diagnosed outpatient (n=15) than inpatient (n=10).
  - These findings were not statistically significant and may have been underpowered due to small sample size.

CONCLUSION

- It is important that physicians identify situations where pSLE screening would be appropriate and include SLE as part of a differential diagnosis
- Understanding conditions that may mimic SLE presentation and knowing which tests to order to may lead to earlier diagnosis and treatment
- Certain minority and state-insured groups may be at risk for delayed SLE diagnosis

Access to outpatient care may cause delayed pediatric SLE diagnosis for at risk populations including Medicaid and Medicare-insured, minority ethnic groups, and non-English speakers. Providers should keep SLE on their differential, as its presentation may mimic other conditions and use of laboratory tests specific to SLE may be underutilized. Improving recognition of SLE presentation among pediatric providers is necessary to quickly identify and treat this disease, as lupus nephritis was seen at twice the frequency in children diagnosed inpatient (n=34) when compared to those who received outpatient care and diagnosis (n=13).

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