



# The Effect of Psychiatric Comorbidity on Healthcare Utilization for Youth With Newly Diagnosed Systemic Lupus Erythematosus

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**ABSTRACT. Objective.** To examine the effect of psychiatric diagnoses on healthcare use in youth with systemic lupus erythematosus (SLE) during their first year of SLE care.

**Methods.** We conducted a retrospective cohort study using claims from 2000 to 2013 from Clinformatics Data Mart (OptumInsight). Youth aged 10 years to 24 years with an incident diagnosis of SLE ( $\geq 3$  International Classification of Diseases, 9th revision, codes for SLE 710.0, > 30 days apart) were categorized as having: (1) a preceding psychiatric diagnosis in the year before SLE diagnosis, (2) an incident psychiatric diagnosis in the year after SLE diagnosis, or (3) no psychiatric diagnosis. We compared ambulatory, emergency, and inpatient visits in the year after SLE diagnosis, stratified by nonpsychiatric and psychiatric visits. We examined the effect of childhood-onset vs adult-onset SLE by testing for an interaction between age and psychiatric exposure on outcome.

**Results.** We identified 650 youth with an incident diagnosis of SLE, of which 122 (19%) had a preceding psychiatric diagnosis and 105 (16%) had an incident psychiatric diagnosis. Compared with those without a psychiatric diagnosis, youth with SLE and a preceding or incident psychiatric diagnosis had more healthcare use across both ambulatory and emergency settings for both nonpsychiatric and psychiatric-related care. These associations were minimally affected by age at time of SLE diagnosis.

**Conclusion.** Psychiatric comorbidity is common among youth with newly diagnosed SLE and is associated with greater healthcare use. Interventions to address preceding and incident psychiatric comorbidity may decrease healthcare burden for youth with SLE.

*Key Indexing Terms:* mental health, pediatrics, systemic lupus erythematosus

Systemic lupus erythematosus (SLE) is a chronic autoimmune condition with significant morbidity and mortality, particularly for patients with childhood-onset disease.<sup>1,2</sup> Healthcare use associated with SLE is high,<sup>3,4</sup> with greatest use occurring in the first year of care.<sup>5</sup> Youth with SLE have higher medical costs than

adults with SLE and their healthy peers,<sup>4,6</sup> with over 7000 hospitalizations per year.<sup>7</sup>

Youth with SLE represent a vulnerable population at risk for healthcare disparities,<sup>3,8</sup> and those with psychiatric comorbidity may be at further risk. One-third of youth with SLE have

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comorbid psychiatric disorders,<sup>9,10</sup> the cause of which can be multifactorial—a result of brain inflammation, stress of chronic illness, and/or its treatment. Studies of adults with SLE and those with other chronic illnesses have shown that comorbid psychiatric disorders increase healthcare use,<sup>11,12</sup> but this association has not been fully studied in youth with SLE. Although we found in a previous study that 18% of youth with SLE had a psychiatric diagnosis prior to their SLE diagnosis and this preceding psychiatric comorbidity was associated with increased healthcare use prior to SLE diagnosis,<sup>13</sup> it remains unknown how it affects care after SLE diagnosis.

This retrospective cohort study further examines the association between psychiatric disorders and healthcare use in youth with SLE. Specifically, we examined the association of psychiatric comorbidity with healthcare visits to ambulatory and acute care settings, during the first year of care. We hypothesized that youth with SLE and psychiatric comorbidity would have lower ambulatory visits, but higher emergency visits and hospitalizations than those without these disorders, as previous studies have shown increased acute care use in children with comorbid medical and psychiatric conditions.<sup>14,15</sup>

## METHODS

**Study design.** We conducted a retrospective cohort study using a large insurance claims database. Given that the dataset is deidentified, an exemption was approved for this study by the institutional review boards at The Children's Hospital of Philadelphia (15-012105), Hospital for Sick Children (1000062686), and Vanderbilt University Medical Center (171241), meaning written consent and approval by a research ethics board were not required.

**Data sources and sample.** Administrative healthcare claims were extracted from Clinformatics Data Mart (OptumInsight) from 2000 to 2013. OptumInsight data are derived from a large, nationwide database of commercial health insurance and Medicare Advantage (C and D) claims. The database contains deidentified patient-level demographics, medical diagnoses, prescription drug use, and healthcare use for approximately 15% of United States residents.

We included individuals aged 10 years to 24 years with an incident diagnosis of SLE. Diagnosis of SLE was defined using previously validated methods as having at least 3 hospital discharge or physician visit claims with an International Classification of Diseases, 9th revision (ICD-9) primary diagnosis code for SLE of 710.0, each at least 30 days apart.<sup>16-18</sup> Incident cases were defined as having at least 1 year of continuous claims data with no SLE codes preceding the index primary diagnosis of SLE. This method has been used for identifying incident SLE cases in medical records databases<sup>19,20</sup> and incident rheumatoid arthritis cases using claims data.<sup>21,22</sup> Healthy controls were identified for comparison of psychiatric disorder prevalence by random selection from age- and sex-matched enrollees during the same eligibility period, without ICD-9 codes specifying a chronic complex condition, per the algorithm developed by Feudtner et al.<sup>23</sup>

Date of diagnosis, defined as the date of first physician visit or admission date of first hospitalization with an SLE claim, was used as the index date. Age was determined at the index date. The study population includes both youth with childhood-onset SLE (cSLE; aged 10-17 yrs) and youth with adult-onset SLE (aSLE; aged 18-24 yrs). The upper age limit was selected to include youth in the process of transitioning from pediatric to adult health systems, a population at risk for suboptimal healthcare utilization and outcomes.<sup>24,25</sup> The lower age limit was set to exclude monogenic causes of very early-onset SLE. All individuals were continuously enrolled for at least 24 months. Only youth with insufficient or discontinuous enrollment

during the specified study period were excluded. There were no exclusions based on disease characteristics, demographics, or comorbidities.

**Exposure groups.** We categorized mutually exclusive groups of youth with SLE as those with: (1) no psychiatric diagnosis, (2) a psychiatric diagnosis in the 12 months preceding SLE diagnosis, and (3) an incident psychiatric diagnosis in the 12 months after SLE diagnosis. Psychiatric diagnoses were identified by a primary or secondary ICD-9 code pertaining to categories of depression, anxiety, adjustment disorder/acute stress, and other psychiatric disorders (Supplementary Table S1, available with the online version of this article).<sup>10</sup> We used a single diagnosis code to identify psychiatric diagnoses because of the low sensitivity of these codes in administrative data related to undercoding.<sup>26</sup> We included primary and secondary diagnoses to identify comorbid medical and psychiatric diagnoses, as well as comorbid depression and anxiety diagnoses.<sup>27</sup>

**Outcome measures.** The primary outcome measure was the number of healthcare visits in the 12-month period following the index date. Healthcare visits were categorized as ambulatory visits, emergency visits (including urgent care), and inpatient visits (ie, hospitalizations). Ambulatory visits were further divided into primary care, rheumatology, and nephrology visits by OptumInsight provider codes. Visit categories were stratified by non-psychiatric and psychiatric visits; psychiatric visits were defined as those with a primary ICD-9 code for a psychiatric disorder.

**Covariates.** We included the following demographic and disease-related covariates: age, sex, race/ethnicity, household education level, geographic region, presence of lupus nephritis (LN) at or after diagnosis, presence of seizure and/or stroke disorder (as indicators of central nervous system [CNS] manifestations of SLE) at or after diagnosis, and index year. OptumInsight derives race and ethnicity from a combination of sources including public records, self-report, and proprietary ethnic code tables and household education level using US census data. Household income data in this database are incomplete, precluding its use as an estimate of socioeconomic status (SES) and emphasizing the importance of including highest household education level as a covariate. We categorized geographic region based on subject residence using US Census Bureau Division state groupings of Northeast, Midwest, South, and West ([https://www2.census.gov/geo/docs/maps-data/maps/reg\\_div.txt](https://www2.census.gov/geo/docs/maps-data/maps/reg_div.txt)). Specific zip codes or states of residence were not available because of the deidentified nature of the dataset, but the sample does include representation from all 9 US census divisions. Presence of LN was identified using a previously validated administrative claims data algorithm requiring > 2 nephrologist visits and > 2 renal ICD-9 codes.<sup>17,18</sup> Presence of seizure or stroke disorder was identified by using a validated algorithm requiring at least 1 ICD-9 code for these conditions.<sup>28-30</sup>

**Statistical analysis.** Two-proportion *Z* tests were used to compare prevalence of psychiatric diagnoses among youth with SLE and healthy controls. Pearson chi-square tests were used to estimate differences in demographic and disease characteristics between the 3 exposure groups. Mean and median numbers of ambulatory visits, emergency visits, and hospitalizations per patient in the year following the index date were calculated. Length of stay for hospitalizations was tabulated. Number of prescription fills for oral glucocorticoids, hydroxychloroquine, and immunosuppressants (mycophenolate mofetil, azathioprine, leflunomide, methotrexate, calcineurin inhibitors, and cyclophosphamide) was also tabulated. To compare the number of visits among exposure groups, unadjusted incidence rate ratios (IRRs) and adjusted IRRs (aIRRs) were estimated using Poisson regression models including all above outlined covariates. As healthcare utilization patterns may differ among children and young adults with SLE, we examined the effect of cSLE vs aSLE by testing for an interaction between age group and psychiatric exposure group. We also performed secondary analyses to compare between psychiatric exposure groups: (1) nonpsychiatric visits to ambulatory, emergency, and inpatient settings; and (2) subcategories of ambulatory visits (primary care, rheumatology, nephrology). Data preparation and analyses were performed using SAS statistical software, version 9.4 (SAS Institute).

## RESULTS

**Demographic and disease characteristics.** We identified 650 youth with an incident diagnosis of SLE. Table 1 summarizes demographic and disease characteristics for this population. Individuals with a preceding psychiatric disorder were slightly older and individuals with an incident psychiatric disorder were slightly younger than those with no psychiatric disorder (19.1 vs 17.6 vs 18.4 yrs, respectively;  $P = 0.01$ ). There were no differences among the 3 groups for race/ethnicity, geographic region, household education level, and medication prescription fills. A higher proportion of individuals with a preceding psychiatric disorder or an incident psychiatric disorder had seizure/stroke disorder, compared with those without a psychiatric disorder (10% vs 14% vs 6%, respectively;  $P = 0.02$ ).

**Prevalence and incidence of psychiatric comorbidity in youth with newly diagnosed SLE.** Psychiatric diagnoses were present for 35% of youth with newly diagnosed SLE (Figure 1). Psychiatric diagnoses preceding SLE diagnosis were present in 122 (19%) individuals, and incident psychiatric diagnoses after SLE diagnosis were present in 105 (16%) individuals. Depression was diagnosed in 117 (18%) individuals; 65 (10%) with a preceding diagnosis and 52 (8%) with an incident diagnosis. Anxiety was diagnosed in 78 (12%) individuals; 46 (7%) had a preceding

diagnosis and 32 (5%) had an incident diagnosis. Adjustment disorders were diagnosed in 65 (10%) individuals; 30 (5%) had a preceding diagnosis and 35 (5%) had an incident diagnosis. Other psychiatric disorders were diagnosed in 110 (17%) individuals including schizophrenic, bipolar, delusional, dissociative, attention deficit, conduct, learning, substance-related, and eating disorders.

We identified 575 age- and sex-matched controls for comparison of psychiatric disorder prevalence. The prevalence for each psychiatric disorder was significantly lower among controls than among youth with SLE. Depression was diagnosed in 68 controls (11.8% vs 18%;  $P < 0.01$ ), anxiety in 43 controls (7.5% vs 12%;  $P < 0.01$ ), adjustment disorder in 23 controls (4% vs 10%;  $P < 0.001$ ), and other psychiatric disorders in 46 controls (8% vs 17%;  $P < 0.001$ ).

**Association of psychiatric comorbidity with overall healthcare use.** Table 2 summarizes healthcare use for youth with SLE during the first year of care, including nonpsychiatric and psychiatric visits to ambulatory, emergency, and inpatient settings. Table 3 shows results of multivariable regression models testing the association between psychiatric comorbidity and overall healthcare use. Compared with youth with no psychiatric disorder, youth with a preceding psychiatric diagnosis had more ambulatory

Table 1. Demographics and health characteristics.

	SLE Full Cohort, N = 650	No Psychiatric Diagnosis, n = 423	Preceding Psychiatric Diagnosis, n = 122	Incident Psychiatric Diagnosis, n = 105	$P^*$
Age, yrs, mean (SD)	18.4 (3.7)	18.4 (3.7)	19.1 (3.6)	17.6 (3.8)	0.01
Female	571 (88)	364 (86)	109 (89)	98 (93)	0.25
Race/ethnicity					0.11
White	367 (56)	223 (53)	84 (69)	60 (57)	
Black	110 (17)	78 (18)	12 (10)	20 (19)	
Hispanic	91 (14)	62 (15)	15 (12)	14 (13)	
Asian	41 (6)	33 (8)	3 (2)	5 (5)	
Unknown	41 (6)	27 (6)	8 (7)	6 (6)	
Region					0.52
Midwest	171 (26)	107 (25)	36 (30)	28 (27)	
Northeast	73 (11)	44 (10)	15 (12)	14 (13)	
South	313 (48)	203 (48)	60 (49)	50 (48)	
West	93 (14)	69 (16)	11 (12)	13 (12)	
Household education level					0.23
< Grade 12	7 (1)	5 (1)	2 (2)	0 (0)	
High school diploma	167 (26)	120 (28)	26 (21)	21 (20)	
< Bachelor's degree	331 (51)	198 (47)	69 (57)	64 (61)	
≥ Bachelor's degree	119 (18)	79 (19)	22 (18)	18 (17)	
Unknown	26 (4)	21 (5)	3 (3)	2 (2)	
Disease characteristics					
Lupus nephritis <sup>a</sup>	159 (25)	98 (23)	28 (23)	33 (31)	0.20
Seizure/stroke disorder <sup>a</sup>	52 (8)	25 (6)	12 (10)	15 (14)	0.02
Medication prescriptions filled <sup>b</sup>					
GCs	483 (74)	309 (73)	91 (75)	83 (79)	0.89
HCQ	506 (78)	327 (77)	93 (76)	86 (82)	0.93
Immunosuppressants	292 (45)	179 (42)	56 (46)	57 (54)	0.41

Values are n (%) unless otherwise indicated. <sup>a</sup> Indicates disease manifestation at or after SLE diagnosis. <sup>b</sup> Indicates medication prescriptions filled during the first year after SLE diagnosis. Immunosuppressants include mycophenolate mofetil, azathioprine, leflunomide, methotrexate, calcineurin inhibitors, and oral cyclophosphamide. \*  $P$  values correspond to Pearson chi-square tests used to estimate differences between the 3 exposure groups. GC: glucocorticoid; HCQ: hydroxychloroquine; SLE: systemic lupus erythematosus.

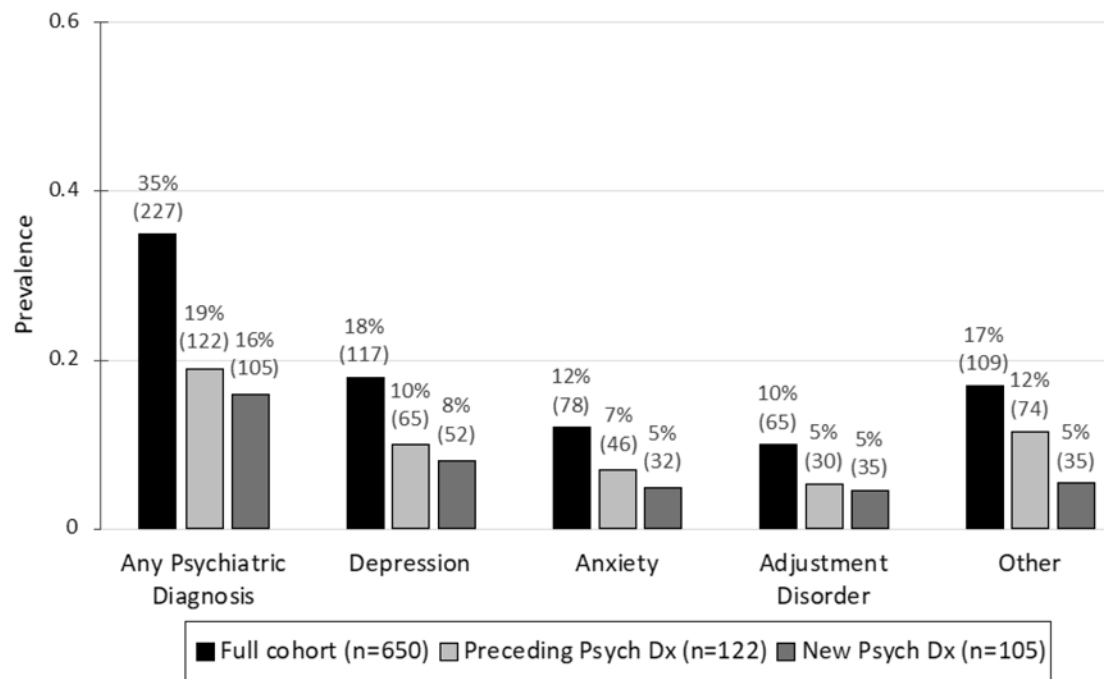


Figure 1. Prevalence of preceding and incident psychiatric diagnoses in youth with newly diagnosed SLE. Dx: diagnosis; psych: psychiatric; SLE: systemic lupus erythematosus.

Table 2. Healthcare utilization in youth with SLE during the first year of care.

Utilization in Year After SLE diagnosis	No Psychiatric Diagnosis, n = 423	Preceding Psychiatric Diagnosis, n = 122	Incident Psychiatric Diagnosis, n = 105	P
<b>Annual Health Visits Per Patient, No.</b>				
<b>Overall visits</b>				
Ambulatory	11.6 (10.0)	17.0 (14.8)	19.7 (15.0)	< 0.001
Emergency	5.1 (8.6)	7.0 (13.2)	9.7 (11.0)	< 0.001
Inpatient <sup>a</sup>	2.7 (7.8)	3.8 (9.0)	5.3 (11.8)	0.02
<b>Nonpsychiatric visits</b>				
Ambulatory	11.6 (10.0)	14.4 (11.7)	18.1 (14.6)	< 0.001
Emergency	5.1 (8.6)	6.9 (13.1)	9.5 (10.9)	< 0.001
Inpatient <sup>a</sup>	2.7 (7.8)	3.5 (8.2)	4.9 (10.7)	0.02
<b>Psychiatric visits<sup>b</sup></b>				
Ambulatory	–	2.7 (7.2)	1.6 (3.3)	0.15
Emergency	–	0.2 (0.9)	0.2 (0.8)	> 0.99
Inpatient	–	0.3 (2.0)	0.4 (1.7)	0.69

Values are mean (SD) or median (IQR). <sup>a</sup> Inpatient visit measures include individuals with at least 1 hospitalization during the observation period. <sup>b</sup> 151 individuals without psychiatric diagnosis had hospitalizations (all nonpsychiatric); 64 individuals with a preceding psychiatric diagnosis had hospitalizations (60 nonpsychiatric and 4 psychiatric); and 53 individuals with a new psychiatric diagnosis had hospitalizations (49 nonpsychiatric and 4 psychiatric). \* P values correspond to type 3 Wald chi-square tests from unadjusted Poisson regression models. SLE: systemic lupus erythematosus.

**Table 3.** Association of psychiatric comorbidity with healthcare utilization in youth with SLE.

Utilization in Year After SLE Diagnosis	Preceding Psychiatric Diagnosis, n = 122	Incident Psychiatric Diagnosis, n = 105
	aIRR (95% CI)	
<b>All health visits</b>		
Ambulatory	1.4 (1.2-1.6)***	1.6 (1.4-1.9)***
Emergency	1.4 (1.1-1.9)*	1.7 (1.3-2.2)***
Inpatient <sup>a</sup>	1.4 (0.9-2.1)	1.4 (0.9-2.2)
<b>Nonpsychiatric visits</b>		
Ambulatory	1.2 (1.0-1.4)	1.5 (1.3-1.7)***
Rheumatology	0.9 (0.7-1.1)	1.2 (1.0-1.4)
Primary care	1.6 (1.3-2.1)***	1.8 (1.4-2.3)***
Nephrology	0.7 (0.5-1.2)	0.6 (0.4-0.9)*
Emergency	1.37 (1.02-1.85)*	1.7 (1.3-2.2)***
Inpatient <sup>a</sup>	1.3 (0.8-2.0)	1.3 (0.9-2.0)

Results are shown from multivariable Poisson regression models comparing annual healthcare visits among youth with new-onset SLE (n = 650) by psychiatric comorbidity status. The reference group is individuals with no psychiatric diagnosis (n = 423). Separate models were used for ambulatory, emergency, and inpatient visits, adjusting for age, sex, race/ethnicity, household education level, geographic region, presence of lupus nephritis, presence of seizure/stroke, and year of diagnosis. <sup>a</sup> Inpatient visit measures include individuals with at least 1 hospitalization during the observation period. \* P < 0.05. \*\* P < 0.01. \*\*\* P < 0.001. aIRR: adjusted incidence rate ratio; SLE: systemic lupus erythematosus.

visits (IRR 1.4, 95% CI 1.2-1.6; P < 0.001) and more emergency visits (IRR 1.4, 95% CI 1.1-1.9; P < 0.05). Compared with youth with no psychiatric disorder, youth with incident psychiatric disorders had more ambulatory visits (IRR 1.6, 95% CI 1.4-1.9; P < 0.001) and more emergency visits (IRR 1.7, 95% CI 1.3-2.2; P < 0.001). The median number of hospitalizations was not significantly different between groups. Also, the length of stay per hospitalization was not significantly different between groups (no psychiatric diagnosis [mean 5.9, SD 6.5], preceding psychiatric diagnosis [mean 5.4, SD 6.4], and incident psychiatric diagnosis [mean 5.7, SD 7.0]). Of the 227 individuals

with a psychiatric diagnosis (preceding or incident), 23 (10.1%) had a single outpatient psychiatric visit during the first year after SLE diagnosis, 56 (24.7%) had > 1 psychiatric visit, and 148 (65.2%) had no psychiatric visits.

*Effect of age group on association of psychiatric comorbidity with overall healthcare use.* Table 4 summarizes results of the analysis to assess the effect of age at onset (cSLE vs aSLE) on the association of psychiatric comorbidity with overall healthcare use. For youth with a preceding psychiatric diagnosis, ambulatory care differed by age group in comparison to those with no psychiatric diagnosis (cSLE IRR 1.2, 95% CI 1.1-1.3; P < 0.01; aSLE IRR 1.5, 95% CI 1.4-1.6; P < 0.001). Emergency visits also differed by age group for youth with a preceding psychiatric diagnosis, compared with those with no psychiatric diagnosis (cSLE IRR 1.1, 95% CI 0.9-1.2; P > 0.05; aSLE IRR 1.8, 95% CI 1.6-2.0; P < 0.001). There was no significant interaction by age group for hospitalizations for those with a preceding psychiatric diagnosis.

For youth with an incident psychiatric diagnosis, there was no significant interaction by age group for ambulatory care visits. Emergency visits differed by age group for youth with an incident psychiatric diagnosis, compared to those with no psychiatric diagnosis (cSLE IRR 2.1, 95% CI 1.8-2.3; P < 0.001; aSLE IRR 1.6, 95% CI 1.5-1.9; P < 0.001). Hospitalizations also differed by age group for youth with an incident psychiatric diagnosis, compared to those with no psychiatric diagnosis (cSLE IRR 2.0, 95% CI 1.7-2.3; P < 0.001; aSLE IRR 1.0, 95% CI 0.8-1.3; P > 0.05).

*Association of psychiatric comorbidity with nonpsychiatric healthcare use and subcategories of ambulatory nonpsychiatric care.* Results from the secondary analysis examining nonpsychiatric healthcare use showed differences by psychiatric comorbidity group (Figure 2). Youth with no psychiatric disorder did not differ from youth with preceding psychiatric diagnoses in nonpsychiatric ambulatory visits (aIRR 1.2, 95% CI 1.0-1.4; P > 0.05), but those with an incident psychiatric diagnosis had more ambulatory visits (aIRR 1.5, 95% CI 1.3-1.7; P < 0.001). Nonpsychiatric emergency visits were also higher for both

**Table 4.** Stratification by childhood-onset vs adult-onset age group: association of psychiatric comorbidity with overall healthcare utilization in youth with SLE.

Utilization in Year After SLE Diagnosis	Preceding Psychiatric Diagnosis, n = 122		Incident Psychiatric Diagnosis, n = 105	
	Childhood-Onset	Adult-Onset	Childhood-Onset	Adult-Onset
	aIRR (95% CI)			
Ambulatory	1.2 (1.1-1.3)**	1.5 (1.4-1.6)***	1.6 (1.5-1.6)****	
Emergency	1.1 (0.9-1.2)	1.8 (1.6-2.0)***	2.1 (1.8-2.3)***	1.6 (1.5-1.9)***
Inpatient	1.3 (1.1-1.4)****		2.0 (1.7-2.3)***	1.0 (0.8-1.3)

Results are shown from multivariable Poisson regression models comparing annual healthcare visits among youth with new-onset SLE (n = 650), including an interaction term for psychiatric comorbidity status and age group. The reference group is individuals with no psychiatric diagnosis (n = 423). Separate models were used for ambulatory, emergency, and inpatient visits, adjusting for age, sex, race/ethnicity, household education level, geographic region, presence of lupus nephritis, presence of seizure/stroke, and year of diagnosis. <sup>a</sup> No significant interaction by age group. \* P < 0.05; \*\* P < 0.01; \*\*\* P < 0.001. aIRR: adjusted incidence rate ratio; SLE: systemic lupus erythematosus.

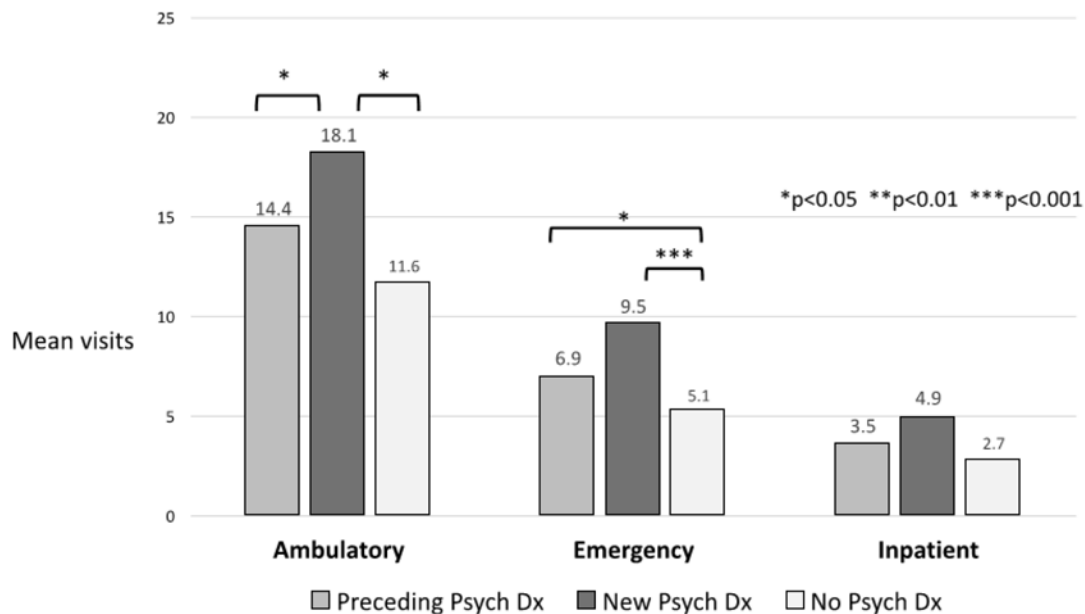


Figure 2. Comparison of annual medical visits by psychiatric status (preceding vs incident vs no psychiatric diagnosis) for youth with newly diagnosed SLE. Results from Poisson regression models comparing utilization of medical (nonpsychiatric) services by youth in the first year after SLE diagnosis according to psychiatric comorbidity status, adjusting for age, race/ethnicity, household education level, region, history of seizures/stroke, and history of nephritis. Dx: diagnosis; psych: psychiatric; SLE: systemic lupus erythematosus.

those with preceding (aIRR 1.37, 95% CI 1.02-1.85;  $P < 0.05$ ) and incident psychiatric diagnoses (aIRR 1.7, 95% CI 1.3-2.2;  $P < 0.001$ ) than for those without psychiatric diagnoses. There were no differences in nonpsychiatric hospitalizations among psychiatric comorbidity groups.

Psychiatric comorbidity groups differed in use of subcategories of nonpsychiatric ambulatory care (Table 3). Compared with youth with no psychiatric diagnoses, youth with preceding psychiatric diagnoses had more primary care visits (aIRR 1.6, 95% CI 1.3-2.1;  $P < 0.001$ ), as did those with incident psychiatric diagnoses (aIRR 1.8, 95% CI 1.4-2.3;  $P < 0.001$ ). Youth with no psychiatric diagnoses did not differ from those with preceding and incident psychiatric diagnoses in frequency of rheumatology visits (aIRR 0.9, 95% CI 0.7-1.1 and aIRR 1.2, 95% CI 1.0-1.4, respectively). Compared with youth with no psychiatric diagnoses, those with incident psychiatric diagnoses had fewer nephrology visits (aIRR 0.6, 95% CI 0.4-0.9;  $P < 0.05$ ); there was no difference for those with preceding psychiatric diagnoses.

## DISCUSSION

The prevalence of psychiatric disorders among youth with SLE is high, and their effect on healthcare use for this population is substantial. Psychiatric diagnoses were present in 35% of our study cohort, similar to previously reported prevalence estimates ranging from 20% to 54%,<sup>31-33</sup> with specific psychiatric diagnoses all higher in youth with SLE than in age- and sex-matched controls in our study. Psychiatric comorbidities in youth with SLE have been associated with poorer health-related quality of life and higher rates of medication nonadherence, a known

risk factor for increased disease activity and damage, potentially requiring increased healthcare resources.<sup>34-36</sup> Direct adverse effects of comorbid psychiatric disorders on healthcare utilization have been shown in adults with SLE and those with other chronic illness.<sup>11,12,37</sup> Although a previous study showed that preceding psychiatric comorbidity was associated with increased healthcare use prior to SLE diagnosis,<sup>13</sup> our reports regarding the effects of psychiatric comorbidities on healthcare use subsequent to SLE diagnosis are a new contribution to the literature.

Only 35% of youth with SLE and psychiatric comorbidity in our cohort had any psychiatric visits. Though we cannot examine reasons for suboptimal psychiatric care, prior studies have reported limited resources, lack of insurance coverage, and patient time burden as primary barriers to mental healthcare.<sup>38,39</sup> Youth with a preceding psychiatric diagnosis and youth with an incident psychiatric diagnosis had much greater ambulatory and emergency healthcare use for psychiatric and non-psychiatric reasons during the first year from SLE diagnosis than those without a psychiatric diagnosis. Individuals with an incident psychiatric diagnosis had the highest nonpsychiatric healthcare use across all settings, including ambulatory rheumatology visits. Those with either a preceding psychiatric diagnosis or an incident psychiatric diagnosis had more primary care provider visits than did those with no psychiatric comorbidity.

There were some notable differences in care patterns between youth with cSLE vs aSLE. Compared with those with no psychiatric diagnosis, youth with cSLE and an incident psychiatric diagnosis had more emergency visits and hospitalizations than their aSLE counterparts. Although the reasons for these findings are unclear, it is possible that newly diagnosed children with

SLE may have more severe psychiatric presentation necessitating acute care, or that progressive psychiatric symptoms are not being identified well in ambulatory settings. This has implications for differential focus of mental health intervention according to age of onset, with possible emphasis on optimizing outpatient intervention for children with SLE to reduce psychiatric care in acute care settings.

Our study suggests that addressing psychiatric comorbidities may decrease healthcare use, particularly during the first year of SLE care when healthcare use is the highest.<sup>5</sup> Mental health interventions that minimize the effect of frequent medical visits are likely to have positive downstream effects on school performance, peer relationships, and family dynamics.<sup>40</sup> Further, mental health interventions that decrease healthcare use could decrease healthcare costs. Studies have shown that adolescents with mental health conditions incur significantly higher total healthcare costs,<sup>41,42</sup> and that adults with SLE who have poorer psychologic functioning incur higher indirect costs.<sup>43</sup> This may be particularly impactful for youth with SLE who have higher medical costs than adults with SLE and their healthy peers.<sup>46</sup> Last, decreased healthcare use can reduce indirect costs to patients and families, such as lost workdays and travel expenses.

Our study emphasizes the importance of early identification of mental health needs for youth with SLE. Routine depression screening can identify at-risk youth and promotes appropriate referral in primary care clinics for patients with other pediatric chronic diseases.<sup>44,45</sup> Pediatric rheumatologists are uniquely positioned to provide mental health screening for youth with SLE. In a large survey of pediatric rheumatologists, 77% of providers responded that routine screening for depression and anxiety in patients with SLE should be conducted, but only 2% reported that standardized screening had been implemented at their center.<sup>46</sup>

Increasing the use of social workers and psychologists in pediatric rheumatology clinics could increase early mental health screening for youth with SLE and help ensure appropriate connection to and follow-up with mental health services. However, access to behavioral health providers within pediatric rheumatology clinics remains an unmet need with a previous Childhood Arthritis and Rheumatology Research Alliance (CARRA) study confirming that over one-third of surveyed centers had no social worker or psychologist.<sup>38</sup> Collaborative relationships with primary care providers also could increase early mental health screening and treatment for youth with SLE. Although a prior study showed lower rates of primary care use in patients with depression symptoms,<sup>9</sup> we are encouraged by our findings of higher primary care use among youth with SLE and psychiatric comorbidities, possibly reflecting improving mental health intervention by primary care providers. Regardless of the strategy used, increasing partnerships to improve integration of medical and mental health services was identified as a priority in a previous survey of patients with rheumatologic disease and their parents.<sup>39</sup>

Database limitations should be acknowledged. First, the cohort includes only privately insured patients and disproportionately low percentages of African American and Latino

American youth. Underrepresentation of those with low SES and racial/ethnic minorities may bias interpretation of these data. Acute care use may be even greater in more representative populations, given increased SLE disease severity and mortality<sup>47</sup> compounded by worse access to outpatient medical<sup>48,49</sup> and psychiatric care<sup>50</sup> in these marginalized populations. Second, attempts to control for confounding related to disease severity were limited to validated ICD-9 algorithms for LN and CNS involvement. However, use of this database enabled us to identify one of the largest national cohorts of youth with newly diagnosed SLE to assess healthcare use for this population across multiple healthcare settings and provider types.

Additional limitations include those inherent to the study design. Although the coding algorithms used to identify SLE cases have been validated for claims data,<sup>16-18</sup> our definition of incident cases of SLE has not been formally validated. This could result in misclassification between comorbid psychiatric groups. In addition, we acknowledge that our efforts to minimize underdiagnosis of psychiatric comorbidities by using the presence of a single diagnosis code to define psychiatric disorders may have inadvertently contributed to overdiagnosis in both the SLE and control cohorts. Last, we recognize that a causal relationship between psychiatric diagnoses and healthcare use cannot be confirmed with this retrospective cohort study design. Regardless of these limitations, however, our study shows that psychiatric diagnoses are prevalent among youth with newly diagnosed SLE and are associated with increased healthcare use.

In conclusion, our study confirms the high prevalence of comorbid psychiatric diagnosis in youth with SLE and that comorbid psychiatric diagnoses are associated with greater ambulatory and emergency care use for both nonpsychiatric and psychiatric-related reasons in the first year after SLE diagnosis. Interventions to address comorbid psychiatric diagnosis in youth with newly diagnosed SLE may have the potential to decrease healthcare burden in this vulnerable population. Further work is needed to better characterize other potentially modifiable factors contributing to increased healthcare utilization, and longitudinal studies will be required to clarify causal relationships between such factors. Additionally, studies incorporating cost-analysis methodology to quantify the financial effect of mental health interventions are urgently needed. This work will help support advocacy efforts for adequate resources to improve outcomes for youth with SLE.

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## ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

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