Healthcare Utilization and Comorbidity Burden among Children and Young Adults in the United States with Systemic Lupus Erythematosus or Inflammatory Bowel Disease

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Objective We sought to assess the feasibility of using a health insurance claims database to estimate the prevalence and health care utilization and costs among children diagnosed with systemic lupus erythematosus (SLE) and inflammatory bowel disease (IBD).

Study design This was a retrospective analysis of the LifeLink insurance claims database for the years 2000-2006. Children (0-15 years) and young adults (16-25 years) with ≥2 diagnosis claims for SLE or IBD were selected as the 2 cohorts of interest. For each member of the SLE and IBD cohorts, 2 individuals were randomly selected for a matched comparison group. All the analyses were descriptive in nature, CI for differences between means and 2 proportions for measures including health care utilization, comorbidity burden were based on *t* tests and 2-group tests of proportions.

Results We identified 278 patients with SLE (prevalence estimate: 7.9 per/100 000 population) and 1174 patients with IBD (33.2 per/100 000 population). The mean annual total medical costs was substantially higher for the SLE (difference: $22 223; 95% CI: $14 961-$29 485) and IBD (difference: $16 238; 95% CI: $14 395-$18 082) cohorts compared with those of the comparator cohort. We observed higher comorbidity burdens in the SLE and IBD cohorts than we saw in the comparator cohort.

Conclusions Administrative claims data can be a useful tool for assessing the comparative prevalence and associated resource utilization of rare conditions such as SLE and IBD. *(J Pediatr 2012;161:662-70)*.

Our understanding of the epidemiology of chronic pediatric conditions has changed substantially over the last 25 years. Increasing immunization has reduced the incidence and mortality of vaccine-preventable infectious diseases and their sequelae and, thanks to advances in medical treatment, children with many conditions that were acutely life-limiting now have extended life expectancies. Despite such progress, the incidence, prevalence, and burden of autoimmune disorders appear to be on the rise, perhaps as a result of industrialization's influence on the environment.[1] Studies analyzing the comparative distribution of the prevalence, burden, and treatment of the diseases of childhood would be useful. The prevalence of some very common conditions of childhood is well documented. For example, the Centers for Disease Control's 2005 "Summary Health Statistics for US Children" reports prevalence statistics for diagnoses of asthma (13%, or 9 million children), allergies (12% for respiratory allergies; 13% for other allergies), and diagnoses of learning disabilities or attention deficit hyperactivity disorder (7% of children 3-17 years, and 9% of boys that age).[2] Similar comparative prevalence and incidence statistics for serious but rare conditions in patients 18 years and younger are not readily available. A PubMed search to test for the existence of easily obtainable published studies, using the algorithm "pediatrics AND chronic AND disease AND comparative AND prevalence" (with limits to "English, all children, full text, and abstracts") and conducted on February 3, 2011, returned 60 articles, all but 2 of them cover only 1 disease or condition[3,4] and none of them provides detailed estimates of disease prevalence; costs, or resource utilization. The present research takes early steps toward generating such comparative analysis by assessing the feasibility of using a health insurance claims database to estimate the prevalence of, and describe health care utilization among, children diagnosed with systemic lupus erythematosus (SLE) and inflammatory bowel disease (IBD).

Methods

This study was a retrospective, longitudinal cohort analysis of the LifeLink database (formerly the PharMetrics Integrated Outcomes Database) for the period

DMARD	Disease-modifying antirheumatic drug
IBD	Inflammatory bowel disease
ICD-9-CM	*International Classification of Diseases, 9th Revision—Clinical Modification*
SLE	Systemic lupus erythematosus

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January 1, 1999- December 31, 2006. LifeLink contains medical and pharmacy insurance claims from commercial health care plans spanning all 4 geographic regions in the United States. For this study, the researchers gained access to a database (ie, 25% random sample) containing information on over 40 million unique individuals who were 25 years of age or younger, who had approximately 2 billion annual health care transactions. This database, containing records on enrollee demographic characteristics (eg, age, sex) and prescription drug, inpatient, and outpatient health care utilization, has previously been used to study health care utilization patterns among pediatric populations.[5-7]

We initially selected patients with a diagnosis of SLE (*International Classification of Diseases, 9th Revision—Clinical Modification* [ICD-9-CM] diagnosis code 710.0 or 695.4) or IBD (ICD-9-CM diagnosis codes 555.x or 556.x), as recorded in the medical claims during the period of January 1, 2000-December 31, 2005 from the larger database. The date corresponding to the first observed SLE or IBD claim during this period was defined as the patient's "index date." The selected patients were required to have at least 1 additional diagnosis claim (in addition to the index claim) for the target condition between January 1, 2000 and December 31, 2006. All patients were required to be continuously enrolled in their health plan for at least 6 months prior to and 12 months following the index date; patients were required to be no older than 25 years of age at the time of their index date. For each patient with the target condition, we created a comparator cohort of 2 randomly selected subjects without IBD or SLE, matched to the index child with IBD or SLE by age (calculated as of year 2005) and sex, and with a minimum health plan enrollment of 6 months before and 12 months after the assigned index date of the corresponding patient. We stratified the selected patients into 2 age groups, including children (0-15 years of age) and young adults (16-25 years of age). A review of the literature guided our decision to use 16 years as the cut-off for "children." Our choice makes this study consistent with prior studies conducted among pediatric IBD and SLE populations that have used a similar cut-off of age less than 16 years.[8-11]

We assessed health care utilization and associated costs for various service settings, including inpatient, outpatient, emergency room, physician office use, and pharmacy during the 6-month pre- and 12-month post-index date period, as well as the number of SLE- or IBD-related prescription drug claims (**Appendices 1-3**; available at www.jpeds.com) and their costs during the 12-month post-index date period. Characterization of inpatient, outpatient, emergency room, physician office visit, and prescription drug use was based on Current Procedural Terminology codes, Healthcare Common Procedure Coding System codes, and National Drug Codes recorded in the claims record. For measurement of prescription drug utilization for the SLE cohort, we grouped prescription drugs into 3 categories: disease-modifying antirheumatic drugs (DMARDs) and non-DMARDs, (**Appendix 1**) and all other prescription medications not related to SLE.

We also assessed the rate of SLE- and IBD-related comorbidities during the 6 month pre- and 12-month post-index date periods. The comorbid conditions selected based on a review of the literature[12-15] included asthma, psoriasis, atopic dermatitis, allergic rhinitis, type 1 diabetes mellitus, general diabetes, multiple sclerosis, rheumatoid arthritis, other central nervous system demyelinating diseases, IBD or SLE, vitiligo, Grave's disease, and thyroiditis. The comorbid conditions for each cohort were ascertained using diagnosis codes (ICD-9-CM). Finally, given the high rate of bone fractures reported among patients with SLE and IBD,[16,17] we assessed the rate of bone fractures (ie, skull, vertebral, rib, pelvic, clavicle, scapula, humerus, radius, hand, neck, other femur, tibia, ankle, and foot) using relevant diagnosis codes during the 12-month post-index date period.[18-20]

This study was approved by the institutional review board at RTI International.

Analysis

Descriptive statistics including mean, frequencies, and percentages characterized the baseline demographics of each study cohort. To estimate the prevalence of SLE and IBD among health plan enrollees 25 years of age and younger, we divided the number of children (0-15 years of age) and young adults (16-25 years of age) identified with SLE or IBD by the sum of the yearly number of children and young adults enrolled continuously in the health plan (regardless of diagnosis) for 6 months before and 12 months after the index date during the period 2000-2005. For each individual in the denominator cohort, July 1, the midpoint of the year was the index date for each study year, via which we assessed continuous enrollment for the 6 months before and 12 months after that index date. Within each study cohort, health care utilization and costs and comorbidity burden were stratified by age, calculated at the index date, into 2 groups, 0-15 years and 16-25 years. CIs for differences between means and 2 proportions for the outlined study measures were based on Student t tests and 2-group tests of proportions. All data management and descriptive analyses were conducted using the SAS, v. 9.1 (SAS Institute Inc, Cary, North Carolina), and Stata, v. 8.2 (StataCorp, College Station, Texas), statistical software packages.

Results

The baseline characteristics for the SLE and IBD cohorts, as well as their matched comparators, are shown in **Table I**. We identified an SLE cohort containing 278 subjects; the IBD cohort contained 1174 subjects. Each disease's cohort is well-matched by its comparator group. On the whole, the IBD cohort is somewhat older on average during the study period, and a slightly higher percentage is male, than is true of the SLE cohort. During the 6-year study period, the prevalence of SLE was 7.9 per 100 000 population (95% CI: 7.0-8.9 per 100 000 population) and the prevalence of IBD was 33.2 per 100 000 population (95% CI: 31.4-35.2 per 100 000 population) (**Figure**). The prevalence estimates were considerably to be greater for young adults (16-25