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Identification and Validation of Lupus Nephritis Cases Using Administrative Data

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Summary

Large administrative databases such as Medicaid billing databases could be used to study care and outcomes of lupus nephritis if these patients could be correctly identified from claims data. We aimed to develop and validate an algorithm for the correct identification of cases of lupus nephritis using ICD-9 billing codes. We used the Research Patient Data Resource (RPDR) query tool at our institution to identify patients with potential lupus nephritis. We compared four ICD-9 code based strategies, identifying patients seen between 2000 - 2007 with Medicaid medical insurance with greater than two claims for a diagnosis of SLE (ICD-9 code 710.0) and a combination of greater than two nephrologist visits and/or renal ICD-9 codes. We assessed performance using the positive predictive value (PPV). 234 subjects were identified and medical records reviewed. Our third strategy, based on a combination of lupus and renal ICD-9 codes and nephrologist encounter claims, had the highest PPV (88%) for the identification of patients with lupus nephritis. This strategy may offer a sound method of identifying patients with lupus nephritis for health services research in addition to serving as a model for using claims data as a way to better understand rare diseases such as lupus.

Keywords

Lupus nephritis; medical claims data

Systemic lupus erythematosus (lupus) is an inflammatory rheumatic disease characterized by autoantibody production and diverse clinical manifestations. Autoantibodies form against a variety of self components and subsequently deposit in the vasculature and organs, activate complement, inflammatory cytokines and immune cells, causing substantial tissue damage¹. Of the rheumatic diseases, lupus has one of the highest mortality rates^{2, 3} and is associated with the most profound sociodemographic disparities, predominantly affecting non-white populations. Prognosis is improved by prolonged, complex and potentially toxic therapies. Depending on the population studied, it is estimated that up to 60% of adults and 80% of children with lupus develop nephritis.⁴⁻¹⁰ Of these, 10 -30% progress to end-stage renal disease (ESRD) necessitating dialysis or renal transplantation within 15 years of diagnosis, even with aggressive treatment.⁴⁻¹⁰ Renal involvement (nephritis) due to lupus is common and ESRD remains a severe complication resulting in an enormous financial impact in healthcare use and productivity loss. In a 4 year lupus cohort study, lupus patients with renal damage incurred over twice the direct costs than those without it¹¹.

While a devastating disease, lupus is rare. The incidence of lupus appears to be increasing in the U.S. over the past 4 decades to greater than 1/1000 individuals³. Previous studies have relied upon relatively small cohorts of well-characterized patients followed at academic medical centers, and thus not generalizable to community settings. Because of this, little is known about the larger epidemiology of lupus nephritis incidence, severity, treatment and outcomes across the country. Lupus nephritis has not been studied in large nationwide medical insurance databases due to the difficulty in correctly identifying patients. Large health insurance databases could provide valuable information in the study of lupus nephritis and its epidemiology and outcomes if these cases could be correctly identified from claims. Previous studies have shown that administrative databases can be effective in identifying patients with various diseases¹². Zgibor and colleagues showed that using an algorithm for selection that included just one additional indicator in addition to the International Classification of Diseases (ICD-9) code is very effective in identifying patients with diabetes (positive predictive values 96-97%)¹³. We aimed to develop and validate an algorithm for the correct identification of lupus nephritis cases using ICD-9 billing codes that would enable such research in the future.

Methods

We employed inpatient and outpatient billing data from Medicaid patients at Brigham and Women's Hospital in Boston to identify lupus nephritis cases. We identified Medicaid patients seen 2000-2007 with > 2 claims for lupus (ICD9 710.0) and compared four separate ICD9-based strategies: 1: greater than 2 claims for any combination of acute or chronic glomerulonephritis (including lupus glomerulonephritis), acute or chronic renal failure, nephritis or nephrotic syndrome (including lupus nephrotic syndrome), renal failure or proteinuria (ICD-9 codes 580.-586. and 791.0), 2: greater than 2 claims for visit to a nephrologist, 3: either strategy 1 or strategy 2 and 4: both strategy 1 and strategy 2.

Independently and blinded to these results, two board-certified rheumatologists performed medical record reviews to validate lupus and lupus nephritis according to American College of Rheumatology Criteria for Systemic Lupus Erythematosus^{14, 15}. To validate the presence of lupus nephritis, we employed the ACR criteria^{14, 15} referring to the presence of nephritis (persistent proteinuria > 0.5 gms/day, or > 3+ on urinalysis, or cellular casts), AND/OR biopsy-proven renal disease attributed to lupus and classified as Class-III-IV or V (focal or diffuse glomerulonephritis or membranous nephropathy) according to the World Health Organization classification¹⁶ for subjects identified by each algorithm. We calculated the positive predictive value (PPV) for each strategy. PPV is calculated as the number with confirmed lupus nephritis divided by the total number subjects within that strategy.

Results

234 subjects were identified and medical records reviewed (Table 1). Of these, PPVs for lupus ranged from 89-92% and PPVs for lupus nephritis ranged from 79-88%. The strategy which produced the best results for identifying lupus was #2 in which we restricted positives as having > 2 ICD-9 codes of 710.0 and > 2 nephrologists visits. This strategy identified 122 patients, 112 of which were validated as lupus (92% PPV). In contrast, the strategy which produced the best results for identifying lupus nephritis was #3 in which we restricted positives as having > 2 ICD-9 codes of 710.0, > 2 nephrologists visits and > 2 renal ICD-9 codes. This strategy identified 116 patients, 102 of which were validated as lupus (88% PPV).

Conclusions

Lupus and lupus nephritis disproportionately afflict disadvantaged groups in our society. Relatively little is known about the epidemiology of lupus nephritis in the community: variation

in access to medical care, timing and types of treatments afforded, specialist care, use of dialysis and renal transplantation, and long-term clinical outcomes. We have developed ICD-9 billing code based strategies for the identification of these patients that could be used in future epidemiologic research concerning lupus nephritis nationwide. In addition, similar algorithms could be used for identification of patients with lupus nephritis from billing data in large administrative databases such as discharge abstracts to study predictors of outcomes from lupus nephritis^{17, 18}.

In identifying patients with lupus nephritis based on billing claims data, there is a trade-off between maximizing PPV and maximizing sensitivity by lowering the number of ICD-9 codes required. Our strategy #3, based on lupus and renal ICD-9 codes and nephrologist encounter claims, had a PPV of 88% for the identification of Medicaid patients with lupus nephritis from billing data at our institution, an urban academic medical center in the U.S. Northeast. This strategy should be further validated in large administrative claims databases and may offer a sound method of identifying patients with lupus nephritis for health services research in addition to serving as a model for using claims data as a way to better understand rare diseases such as lupus.

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Positive Predictive Values of 4 Algorithms to identify Lupus Nephritis from Billing Data for Medicaid patients

Table 1

	> 2 ICD-9 710.0 +	Total identified	Lupus	PPV Lupus, 95% CI	Nephritis	PPV Nephritis, 95% CI
1	> 2 renal ICD-9 codes	228	203	89% (85 – 93)	183	80% (75 – 85)
2	> 2 nephrologist visits	122	112	92% (86 – 97)	105	86% (80 – 92)
3	Both of above	116	106	91% (86 – 96)	102	88% (82 – 94)
4	Either of the above	234	209	89% (85 – 93)	186	79% (74 – 85)

PPV= positive predictive value, CI= confidence interval