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Assessing the Concordance of Clinical Classification Criteria for Lupus Between Electronic Health Records and a Physician Curated Registry

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Abstract

We developed a computable phenotype for systemic lupus erythematosus (SLE) based on the Systemic Lupus International Collaborative Clinics clinical classification criteria set for SLE. We evaluated the phenotype over registry and EHR data for the same patient population to determine concordance of criteria detected in both datasets and to assess which types of structured data detected individual classification criteria. We identified a concordance of 68% between registry and EHR data relying solely on structured data.

Keywords:
Electronic health records, phenotype, systemic lupus erythematosus.

Introduction

Clinical classification criteria are often used to understand the clinical presentation of diseases with complex or varied presentations. Electronic health records (EHR), now commonly used in the course of routine health care throughout the United States provide a rich source of data [1], including diagnoses, lab results and medication use that can be used to enhance understanding of the development, manifestation and treatment of complex disease over time.

Our team developed a rules-based algorithm to identify patients with Systemic Lupus Erythematosus (SLE), a complex systemic autoimmune disease that affects multiple organ systems and has diverse manifestations that develop over time [2]. This computational phenotype is based on the Systemic Lupus International Collaborating Clinics (SLICC) classification criteria for SLE [3].

We evaluated our SLICC-based computational phenotype in a physician-validated registry and the medical record data for the same patient population: 1) to assess the concordance of criteria detection in these two distinct datasets; and 2) to better understand whether medical records can be used as a substitute for manual chart abstraction in the identification of clinical classification criteria for a complex autoimmune disease.

Methods

Established in 1991, the Chicago Lupus Database (CLD) is a physician validated registry of 1,052 patients with possible or definite lupus according to the revised 1982 American College of Rheumatology classification criteria [4][5]. The CLD has laboratory data, symptoms and paitent demographics based on each known visit. If a patient was referred, previous history information from the notes are documented. The data is entered in MEDLOG [6] which is then compiled into the CLD.

The Northwestern Medicine Electronic Data Warehouse (NMEDW) is the primary data repository for of all the electronic health records of patients who receive care within the Northwestern Medicine system. Established in 2002, the NMEDW contains records for over 3.8 million patients. Patients in the CLD consented to allow their medical records to be used for research and their medical records can be found in the NMEDW using a medical record number (MRN) stored in the CLD. Review medical records in the NMEDW was approved by the Northwestern University IRB.

We identified 878 patients who had definite lupus according the SLICC criteria [3], as defined by meeting at least one clinical and one immunolgical criteria and meeting 4 or more criteria overall. After removing patients who did not have medical records in the NMEDW, there were 818 patients remaining. To ensure sufficient depth of data for analysis by our algorithm, we removed any patients who had less than four encounters documented in the NMEDW, reducing the cohort size to 472. Finally, we assessed our the full algorithm over the patient medical record data. Only 408 of those patients who also met the SLICC criteria for definite lupus in the CLD also met the criteria for definite SLE based on their medical record data.

The SLICC clinical criteria-based algorithm for detection of SLE was run over each patient in the cohort and each of the 17 individual criteria was scored for presence or absence in the CLD and the NMEDW. A combination of ICD9/10 codes and laboratory results were used to determine whether each individual criterion was satisfied.

A criterion was considered discordant when it was present in either the CLD or NMEDW (but not both) for a given patient record. A KNIME (3.4.2) workflow [7] was developed to process each patient data set and determine the number of concordant and discordant criteria. For discordant criteria, we determined whether the criterion was present in the CLD or the NMEDW. For each criterion, we used McNemar's test to see if the NMEDW and CLD results were different. A p value $< .05$ was used to determine significant difference. Descriptive statistics were calculated using SAS software version 9.4 (SAS Institute)Results

Table 1 describes the basic demographics of the cohort we assessed that met the SLICC classification criteria for definite SLE in the CLD and NMEDW. Our cohort is predominantly female, white, and had an average disease onset age of 30 years. The gender distribution and age of onset is consistent with previous studies demonstrating the predominance of SLE among women that develops relatively early in life [8]. The racial and ethnic distribution is consistent with the patient

population receiving treatment within the Northwestern Medicine System.

Table 1— Cohort Demographics (N=408)

Sex	**% of Cohort**	
Female	92%	
Male	8%	
Race/Ethnicity	**% of Cohort**	
Caucasian	48.1%	
African American	30.5%	
Hispanic	12.4%	
Asian	7.8%	
Other	1.2%	
Age	**Mean Years**	**SD**
Current	50 years	13.48
At Diagnosis	30 years	9.69

To further understand the concordance between the registry and the medical record data, we determined the number of present and absent criteria that were concordant as well as the average number of criteria detected per patient in each data set. The results of this assessment are shown in Table 2. Within the concordant criteria, on average, there were 5 that were concordant and present, 7 that were concordant but absent. When evaluating the criteria set over the CLD, on average, we detected 8 criteria per patient, while we detected 7 criteria per patient using their medical record data. A paired t-test for significance resulted in a p-value of .59, indicating that the results are not significantly different.

Table 2— Overall Concordance between Registry and Medical Record Data for Patients Meeting SLICC Criteria (out of 17 total).

Number of Criteria Per Patient	**Mean**	**Median**	**SD**
Overall Concordant Criteria	11.6	12	1.7
Present Concordant Criteria	4.9	5	1.8
Absent Concordant Criteria	6.7	7	2.0
Criteria Detected in CLD	7.9	8	2.1
Criteria Detected in EDW	7.3	7	2.1

Discussion

We developed a clinical classification criteria-based computational phenotype to identify patients with SLE in a physician validated SLE registry and in a large medical record data repository and assessed concordance of the overall algorithm and individual criteria that comprise the algorithm. For those patients who satisfied the classification criteria for definite lupus in both the registry and the medical record data set, there were, on average, 12 concordant criteria out of 17, 5 of which were concordant and present in both the CLD and NMEDW, 7 of which were concordant and absent in both the CLD and NMEDW. When we assessed concordance for individual criterion, we found that concordance was highest for criteria that were based on laboratory data. The highly discordant criteria were primarily clinical criteria detected with diagnosis codes that may not always be documented as part of routine clinical care or may be documented in locations within the medical record, such as physician notes, that are not easily queried using simple structured data elements, such as arthritis, oral ulcers, and serositis.

Conclusion

Using a computational phenotype for SLE based on the SLICC clinical classification criteria, we demonstrated an overall high concordance of 68% between physician validated registry information and data found in patient medical records suggesting medical record data can be used to supplement manual chart abstraction for the application of clinical classification criteria to patients with complex disease.

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