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Utilization of Ambulatory Physician Encounters, Emergency Room visits and Hospitalizations by SLE patients

A 13 year population health study

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Abstract *(word count =250)*

Objective: To determine total physician encounters, emergency room (ER) visits and hospitalizations in an incident cohort of systemic lupus erythematosus (SLE) cases and matched control patients over 13 years.

Methods: A retrospective cohort study was performed utilizing administrative health care data from approximately 1 million people with access to universal healthcare. Using ICD-9 and ICD-10 diagnostic codes, 7 SLE case definitions were used. Each case was matched by age and gender to 4 randomly selected controls. Data included physician billings, ER visits and hospital discharges over 13 years.

Results: The number of incident SLE cases varied from 564 to 4,494 depending up the case definition. The mean age varied from 47.7 to 50.6 years and the proportion of females from 78.0 to 85.1%. SLE utilization of physicians was highest in the index year, declining significantly thereafter for all case definitions. By the fourth year, encounters with subspecialty physicians fell by 60% (Rheumatologists), 50% (Internal medicine) and 31% (other physicians). In contrast, visits to family physicians fell by only 9%. Visits to the ER and hospital admissions for SLE cases were also more frequent early in the disease and fell significantly over the study for both ER visits (all case definitions) and hospitalizations (2 of 7 case definitions).

Conclusion: In SLE patients, health care utilization is highest in the first few years following the diagnosis which is also the time of maximal involvement by rheumatologists. Utilization declines over time and encounters with patient's family physicians predominate over other physician groups.

Significance and Innovations

- In a population health study utilizing 7 case definitions for SLE we demonstrate a consistently higher utilization of physician resources by SLE patients compared to age and gender matched controls over 13 years of observation.

- Rheumatology and other subspecialty physician resources are utilized most intensely in the first 4 years following the diagnosis of SLE.

- Emergency room visits and hospitalizations are most frequent early in the course of disease, falling gradually thereafter.

Systemic lupus erythematosus (SLE) is one of the most frequent autoimmune inflammatory rheumatic diseases, characterized by its higher frequency in women and certain racial/ethnic groups (1). It has the potential to affect any organ system in the body. The clinical manifestations vary from subtle, slowly progressive symptoms such as fatigue, rash and arthritis to rapidly progressive and potentially life threatening disease due to renal or nervous system involvement. The clinical outcome for both mild and severe cases is improved by a prompt and accurate diagnosis, appropriate access to health care providers and institution of evidence based treatments.

Planning for the provision of future health resources required for the diagnosis and treatment of SLE patients starts with an assessment of previous and current resource utilization. Different research methodologies have been used to address this, including case-control strategies in tertiary referral centers, observational cohorts and population health administrative datasets. Resource utilization and associated costs have been examined in various geographic locations including the USA (2-7), Canada (8) and other countries (9-11). This is appropriate as findings are influenced by health care system delivery which is highly variable. Due to the rapid pace of reform of health care delivery and the chronicity of SLE which extends over a patient's lifetime, it is necessary to periodically update utilization in representative geographic locations. As part of an overall evaluation of health care resource utilization by SLE patients in our region we examined the total physician encounters, emergency room visits and hospitalizations in SLE and control patients over 13 years using a validated population health dataset.

Materials and Methods

Study populations and controls: This was a retrospective cohort study of patients with a diagnosis of SLE within the Nova Scotia Medical Services Insurance (MSI) program. Nova Scotia is a Canadian province of approximately 1 million inhabitants. There are 3,500 physicians in Nova Scotia of which approximately 50% work in primary care, 7% are general internists and 0.3% are adult rheumatologists. Health care services including acute and elective hospitalizations and ambulatory physician visits are universally provided as specified under the Canada Health Act. The eligible population for the study of prevalent cases was Nova Scotia residents who were enrolled in the MSI program between April 1st 1997 and March 31st 2011. This excludes First Nation Canadians and members of the Canadian armed forces. Incident cases of SLE were defined as those without a physician billing for the same diagnosis in the preceding 5 years (12). Prevalent cases included both incident and non-incident cases. Patients with SLE were matched one to four by age and gender to a control cohort of patients who were also enrolled in the MSI program at the time of their matched case's date of diagnosis and who never had a diagnosis of SLE or other connective tissue diseases.

The data was obtained from existing databases accessed through the Population Health Research Unit (PHRU) (current title Health Data Nova Scotia (HDNS)) in the Department of Community Health & Epidemiology at Dalhousie University in Halifax, Nova Scotia, Canada. Within this unit there are secure research computing facilities on

site and access to data is governed by PHRU/HDNS Data Access Guidelines and Procedures. Electronic utilization data from the Nova Scotia Senior Pharmacare Program (NSSPP) for seniors (age≥65), the Canadian Institute of Health Information (CIHI) Hospital Discharge Abstracts database and the MSI Physician Billings database were linked via medical services insurance (MSI) number. The study protocol was reviewed and approved by the Capital Health Research Ethics Board. Informed consent from individual patients was not required as the study utilized secondary administrative data.

Case definitions for identification of SLE cases and validation: The following 7 individual case definitions, 3 of which were based upon previously published work, were used to identify cases of SLE in the administrative databases. We have previously validated these case definitions against a clinical dataset of SLE patients and controls (13). The diversity of the decision rules provides a range of sensitivity and specificity for case ascertainment, thus permitting a degree of sensitivity analysis of health care utilization.

#1 Any encounter: Any single diagnostic code for SLE by a physician.

#2 MacLean (14): Two physician visits for SLE at least 2 months apart.

#3 MacLean/Lacaille (12): MacLean-like algorithm with Lacaille variation (excluded individuals with at least 2 visits, at least 2 months apart, subsequent to the second SLE visit, with 2 identical diagnoses of other inflammatory arthritides and connective tissue

diseases (RA, psoriatic arthritis, ankylosing spondylitis, and other spondylarthropathies, scleroderma, Sjogren's syndrome, dermatomyostis, polymyositis, other connective tissue diseases, primary systemic vasculitis) and those where a diagnosis of SLE by a non-rheumatologist was not confirmed if/when the individual saw a rheumatologist.

#4 Shipton-like: Three SLE diagnostic billing codes, over any time period, rather than in 3 consecutive years as described by Shipton et al (15).

#5 Hospitalization: At least one hospitalization where SLE was in the diagnostic codes.

#6 Rheumatologist: At least one SLE code contributed by a rheumatologist.

#7 Combination: MacLean-like algorithm (2 non-Rheumatology physician visits for SLE at least 2 months apart, within a 2 year period) or at least one SLE code contributed by a rheumatologist or at least one hospitalization where SLE was in the diagnostic codes and Lacaille variation, i.e. excluding individuals with at least 2 visits, at least 2 months apart, subsequent to the second visit, with 2 identical diagnoses of other inflammatory arthritides and connective tissue diseases (RA, psoriatic arthritis, ankylosing spondylitis, and other spondylarthropathies, scleroderma, Sjogren's syndrome, dermatomyostis, polymyositis, other connective tissue diseases, primary systemic vasculitis) and excluding those where a diagnosis of SLE by a non-rheumatologist was not confirmed if/when the individual saw a rheumatologist.

Data collection: Individual level data were obtained. Computerized claims were linked by encrypted health card number to the Canadian Institute of Health Information (CIHI)

Hospital Discharge Abstracts and MSI Physician Billings for fiscal years from April 1st 1997 and March 31st 2011.

The following ICD-9 and ICD-10 diagnostic codes were used:

Systemic lupus erythematosus (ICD-9: 710.0. ICD-10: ICD-10: M 32, M32.1, M32.8, M32.9).

Rheumatoid arthritis (ICD-9: 714.0, 714.1, 714.2. ICD-10: MO5 – MO5.9, MO6.0, MO6.8, MO6.9).

Psoriatic arthritis (ICD-9: 696.0. ICD-10: L40.5)

Ankylosing spondylitis (ICD-9: 720.0. ICD-10: M45)

Other spondylarthropathies (ICD-9: 720.1, 720.2, 720.8, 720.9. ICD-10: M46.0, M46.1, M46.2, M46.3, M46.4, M46.5 M46.8, M46.9)

Scleroderma (ICD-9: 710.1. ICD-10: M34)

Sjogren's syndrome (ICD-9: 710.2. ICD-10: M35.0)

Dermatomyositis (ICD-9: 710.3. ICD-10: M33.1, M33.9)

Polymyositis (ICD-9: 710.4. ICD-10: M33.2)

Other connective tissue diseases (ICD-9:710.5, 710.8, 710.9. ICD-10: M35.1, M35.2, M35.8, M35.9)

Primary systemic vasculitis: (ICD-9: 446.0, 446.2, 446.4, 446.5, 446.7, 447.6. ICD-10: D69.0, M31.0, M30.0, M31.3, M31.4, M31.5, M31.6, M31.7, M31.8, M31.9).

Selected co-morbidities over the study period were expressed as a proportion of affected SLE cases and controls using the following ICD-9 and ICD-10 diagnostic codes:

Cancer: all malignancies except lymphoma (ICD-9: 140-208, excluding 200-203. ICD-10: C00-D48, excluding C81-C85;

Coronary heart disease (CHD) (ICD-9: 410-414. ICD-10: I20-I25)

Cardiovascular disease excluding CHD (ICD-9**:** 390-459 excluding 410-414. ICD-10: I100-I99 excluding I20-I25)

Diabetes (ICD-9: 250. ICD-10: E10-E14)

Infection (ICD-9: 001-139, 465, 480-488. ICD-10: A00-B99, J06,J10-J18)

Lymphoma (ICD-9: 200-203. ICD-10: C81-C85)

Mental health (ICD-9: 290-319. ICD-10: F00-F99)

Renal impairment (ICD-9: 580-589. ICD-10: N00-N19)

Statistical analysis: The data were analyzed with SAS software v8.3 and SAS/Stat software 12.1 v9.3 (SAS Institute Inc., Cary N.C., USA). Descriptive statistics were used to characterize the prevalent SLE and control cohorts and variables included age, gender, number of ambulatory visits, number of emergency room visits, number of hospitalizations, and diagnosing physician groups. Censorship of data was addressed by using patient year exposures which was defined by each individual's utilization or eligibility for utilization in number of years between their incident diagnosis or matching and the last contact with the health service (i.e. physician contact, emergency room visit

and hospitalization). Linear regression and negative binomial models at the aggregate data level were run to examine differences in utilization between cases and controls and utilization over time. Models were also adjusted for the interaction of index year of utilization and case/control group. The log of patient year exposure was used as the offset in negative binomial models. The relationship between individual co-morbidities and case definition group was examined using the chi-square test for independence. The analysis was run separately for each case definition.

Results

Patients and controls: The number of SLE cases identified in the administrative datasets and available for study over the 13 years of observation varied with the 7 case definitions used (Table 1) (13). The definition with the greatest sensitivity was #1 (a single encounter with any physician) and the most specific definition was #5 (hospitalization for which SLE was listed as one of the diagnostic codes). Using these two definitions the number of incident cases of SLE varied from 564 to 4,494 and the number of prevalent cases varied from 2,210 to 12,606 over the period of study. Cases had a comparable mean age and gender distribution regardless of the case definition for SLE (Table 1). There was no significant difference between SLE cases and controls in the number of patient year exposures.

Physician consultations: Starting from the index year (i.e. year of diagnosis of SLE in this incident cohort) the number of physician encounters per patient per year for cases and controls over the duration of followup is illustrated in Figure 1. SLE cases were

identified using the 7 case definitions for SLE. Utilization reflects the combination of outpatient ambulatory assessments and inpatient consultations by family physicians, general internists, rheumatologists and other physician groups. For all case definitions there was significantly higher utilization by SLE cases compared to controls. ($p<0.001$) In SLE cases the utilization was highest in the index year and fell thereafter. There was a significant fall in utilization by SLE cases over time ($p<0.001$) with all case definitions with the exception of case definition #1 (any physician encounter) For four SLE case definitions the utilization curves dipped substantially during the last 3 years of observation. The same observation occurred for the matched control group which suggests that the cause was unrelated to SLE. The gradual increase in utilization in the controls over time was most likely due to the change in health care needs with increasing age.

The breakdown in physician encounters by specialty group and the change over time is illustrated in Figure 2 using SLE case definition #7 (Combination). For all case definitions the utilization of all physician groups was significantly higher for SLE cases than for their matched controls ($P<0.01$). This was apparent both at the initial encounter and over time. There was a significant fall in the utilization of all physician groups by SLE cases over time ($p<0.01$) with all case definitions. Subspecialty encounters was highest early in the disease course and by the fourth assessment the frequency fell by 60% (Rheumatologists), 50% (Internal medicine) and 31% (other physicians). In

contrast, the frequency of visits to family physicians only fell by 9% over the same time and remained high for the duration of study.

Emergency room visits: Utilization of the emergency room by SLE cases and controls is illustrated in Figure 3. Regardless of which case definition for SLE that was used, visits to the emergency room were significantly more frequent by SLE cases (P<0.001) which was most apparent early in the disease. There was a significant fall in emergency vists by SLE cases over time (p<0.001) with all case definitions.

Hospitalizations: Hospital admission rates in SLE cases and controls are illustrated in Figure 4. For SLE cases, regardless of the definition, the hospital admission rate was significantly higher (P<0.001) compared to controls. This was especially true early in the disease course. There was a significant fall in hospitalizations for SLE cases over time (p<0.05) with case definitions #2 (McLean) and #5 (Hospitalization) but not with other case definitions. The dramatic spikes in hospital admissions seen among the cases and the controls most likely reflect random events among the relatively small numbers of cases and controls with at least 8-10 years of follow-up. Not surprisingly, patients identified through a hospital admission associated with SLE (case definition #5) had a high admission rate over time and the data point for the admission rate at the first encounter was so high (7.23) that it negated the ability to discriminate other hospitalization curves and was not included in the graph.

Co-morbidities: The proportions of SLE patients and matched controls with selected co-morbidities over the period of study are summarized in Table 1. Regardless of which

SLE case definition was used, all of the co-morbidities were more frequent in SLE cases compared to their matched controls ($p<0.01$). Within SLE cases, patients identified through a hospital admission associated with SLE (case definition #5) had a higher proportion with co-morbidities.

Discussion

Health care utilization and associated costs have been studied in SLE and other chronic rheumatic diseases using different research methodologies. Most studies have involved secondary use of health administrative data on prevalent cohorts followed over short time frames. Some investigators have focused on disease subsets and demonstrated enhanced utilization and costs in association with specific manifestations (8)(11). In our study we wished to examine the change in health care utilization in the total population of SLE patients from the time of diagnosis over the ensuing years and to compare it to that seen in population controls. To this end we studied an incident cohort of SLE patients followed for up to 13 years using health administrative data which was previously validated against a clinical dataset.

Studies of health care utilization have consistently found that it is higher in SLE patients than in comparator groups of patients (4, 5, 10, 16). Utilization may be influenced by a variety of factors, including disease severity (17) (higher in lupus nephritis (8, 16) and neuropsychiatric lupus (11, 16)), race/ethnicity (lower in Hispanics (18)), and the type of the health care delivery (higher in fee for service system (3)). Previous studies have

been cross-sectional, retrospective and longitudinal in design, using prevalent rather than incident SLE cases and informed by observational data collected over 1 to 7 years. In the current study, utilization was assessed in the first year that the incident case occurred in the dataset which was taken as the year of diagnosis of SLE. Subsequent utilization was tracked for up to 13 years. Seven case definitions for SLE with a range of sensitivities and specificities were used in order to capture the full spectrum of SLE. The accuracy of these definitions and the identification of incident and prevalent cases of SLE have been published in detail elsewhere (13). Their use in this and future studies allows a form of sensitivity analyses for utilization and costs. The cases identified by each definition were matched by age and gender to 4 controls. The findings were remarkably consistent. Regardless of the SLE case definition, physician encounters were highest in the year of diagnosis, trending lower in subsequent years but always remained above that in matched controls.

It is to be expected that multiple physician groups will be involved in the diagnosis and subsequent care of patients with SLE given the protean manifestations of the disease. In the current study, physician encounters were categorized into those with family physicians, general internists, rheumatologists and others. Utilization of all 4 physician groups was substantially higher in SLE cases compared to controls over the entire study. Encounters with family physicians, who are responsible for delivering primary care in the Canadian health care system, were the most frequent. Subspecialty care was utilized most frequently early in the disease course, falling substantially over the

next 3 years. In contrast the frequency of encounters with family physicians changed relatively little over time. The interpretation and implications of these observations are two-fold. First, access to subspecialty care is most frequent and thus most critical around the time of diagnosis of SLE and in the first few years of followup when the disease is being stabilized. Second, the utilization of family physicians remains high but relatively constant over the course of the illness which underlines the important role that family physicians play in the long-term management of SLE patients. Given the need to prevent and treat comorbidities, which were universally more frequent in SLE patients compared to matched controls in our study, the strategic delivery of effective care will require ongoing co-ordination by rheumatologists and primary care physicians.

The frequency of visits to hospital emergency rooms and admissions to hospital are indicators of the impact of a medical illness. Previous studies had demonstrated that both are higher in patients with SLE compared to controls (5, 10, 19, 20). The current study confirms this observation, but also demonstrates a consistent change in the pattern of utilization over the 13 years of observation. Utilization of both services was highest in the first year following the diagnosis of SLE (index year), and declined thereafter to eventually reach the same frequency as in controls by the end of the study. This may reflect a survivor effect due to excess mortality in SLE cases early in the disease course (21) that are thereby removed from the dataset. An alternative explanation is that following the diagnosis of SLE, appropriate treatment is initiated

leading to improved disease control and reduced need to visit the emergency room or require admission to hospital.

There are a number of strengths to the current study. First, due to the Canada Health Act all patients accessed health care through a single provider, ensuring comprehensive data capture for all physician encounters, emergency room visits and hospitalizations. Second, the Nova Scotia population is stable with a mix of urban and rural communities and a range of socioeconomic groups and thus represents a general Canadian population. Third, the use of 7 validated case definitions reduces the risk of bias that could arise from using a more limited strategy for identifying cases and controls.

There are also some limitations to the study. First, due to the homogenous nature of the Nova Scotia population it was not possible to examine the effect of race/ethnicity on health care utilization. Second, Athough the definition of incident cases was in agreement with traditional methodology in population health studies (12) it would not have excluded SLE patients with longstanding disease who relocated to Nova Scotia during the period of study. Third, the range in the proportion of female patients between 78.0% to 85.1% across case definitions is lower than the traditional 90% in most lupus cohorts, albeit that these are usually drawn from subspecialty clinics and inpatient units in health care facilities. Two recent population based studies revealed a gender distribution that was closer to our cohort. The Michigan Lupus Epidemiology and Surveillance program of incident SLE diagnosed by a rheumatologist reported a female

predominance of 85.4% in the total population and 83.5% in white patients (22). The Georgia Lupus Registry on incident SLE patients who fulfilled the ACR classification criteria (23) had a similar gender distribution with a female predominance of 85.4% in the total population and 85.5% in white patients. Fourth the cases were not stratified for disease activity or severity, in which utilization patterns may have been different. Finally, comparative data on patients with other chronic disease in a population of similar age and gender was not available. Future studies will address these deficiencies and determine the economic costs of health care utilization in this cohort of SLE patients.

(Word count: Introduction to Discussion: 3,218)

Table 1: The proportion of SLE patients and matched controls with selected co-morbidities

	Any encounter	MacLean	MacLean Lacaille	Shipton	Rheumatologist	Hospital	Combination
SLE	N=3869	N=2075	N=1244	N=1860	N=1628	N=508	N=2559
Mean age (years)	48.8	50.6	48.8	48.8	47.7	49.2	50.0
Female (%)	78.0	81.8	82.9	81.2	85.1	81.4	81.1
Comorbidity*							
Cancer	0.35	0.35	0.35	0.35	0.35	0.40	0.35
CHD	0.28	0.29	0.29	0.29	0.27	0.42	0.30
CVD	0.79	0.82	0.80	0.83	0.82	0.88	0.82
Diabetes	0.19	0.18	0.18	0.18	0.19	0.24	0.19
Infection	0.86	0.88	0.86	0.88	0.88	0.90	0.87
Lymphoma	0.07	0.06	0.05	0.07	0.07	0.11	0.07
Mental health	0.77	0.78	0.78	0.77	0.79	0.75	0.77
Renal impairment	0.14	0.16	0.17	0.17	0.18	0.40	0.17
Controls	N=15476	N=8300	N=4976	N=7440	N=6512	N=2032	N=10236
Cancer	0.20	0.20	0.21	0.20	0.19	0.19	0.20
CHD	0.15	0.15	0.16	0.15	0.13	0.16	0.15
CVD	0.51	0.51	0.52	0.51	0.48	0.51	0.51
Diabetes	0.15	0.15	0.15	0.15	0.13	0.14	0.14
Infection	0.55	0.54	0.55	0.55	0.55	0.56	0.55
Lymphoma	0.02	0.02	0.02	0.02	0.02	0.01	0.02
Mental health	0.52	0.52	0.52	0.52	0.52	0.53	0.52
Renal	0.05	0.05	0.05	0.05	0.04	0.05	0.05

- Cancer: all malignancies except lymphoma; CHD: coronary heart disease; CVD: cardiovascular disease excluding CHD.

Figure 1

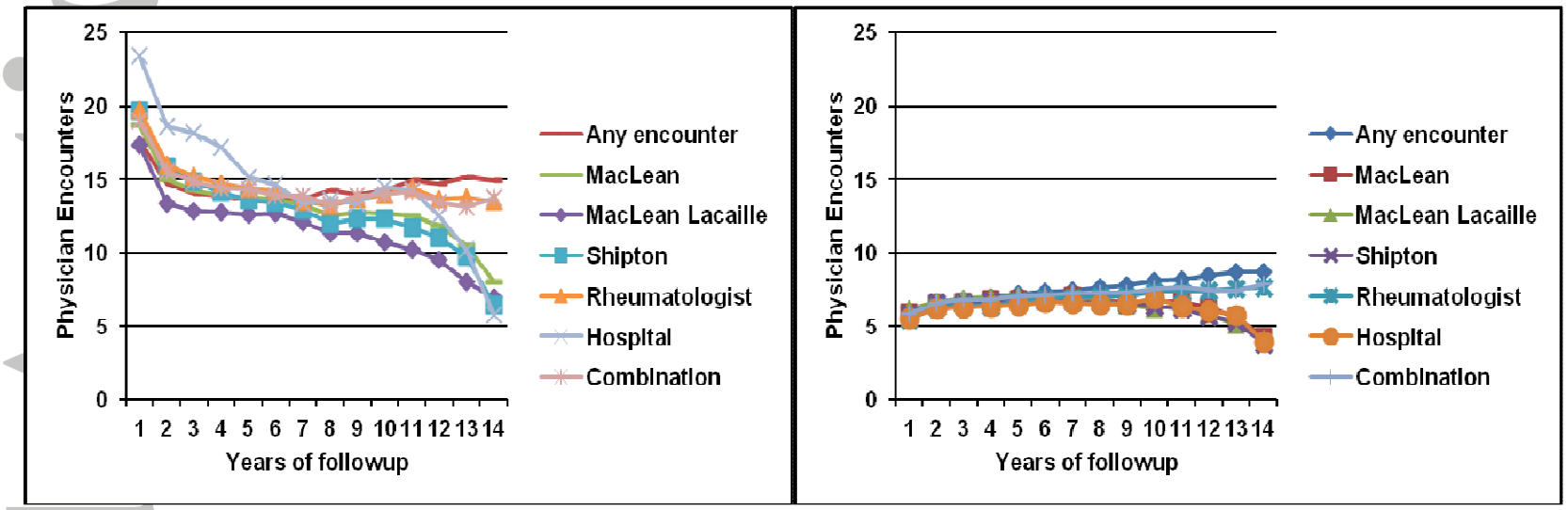


Figure 2

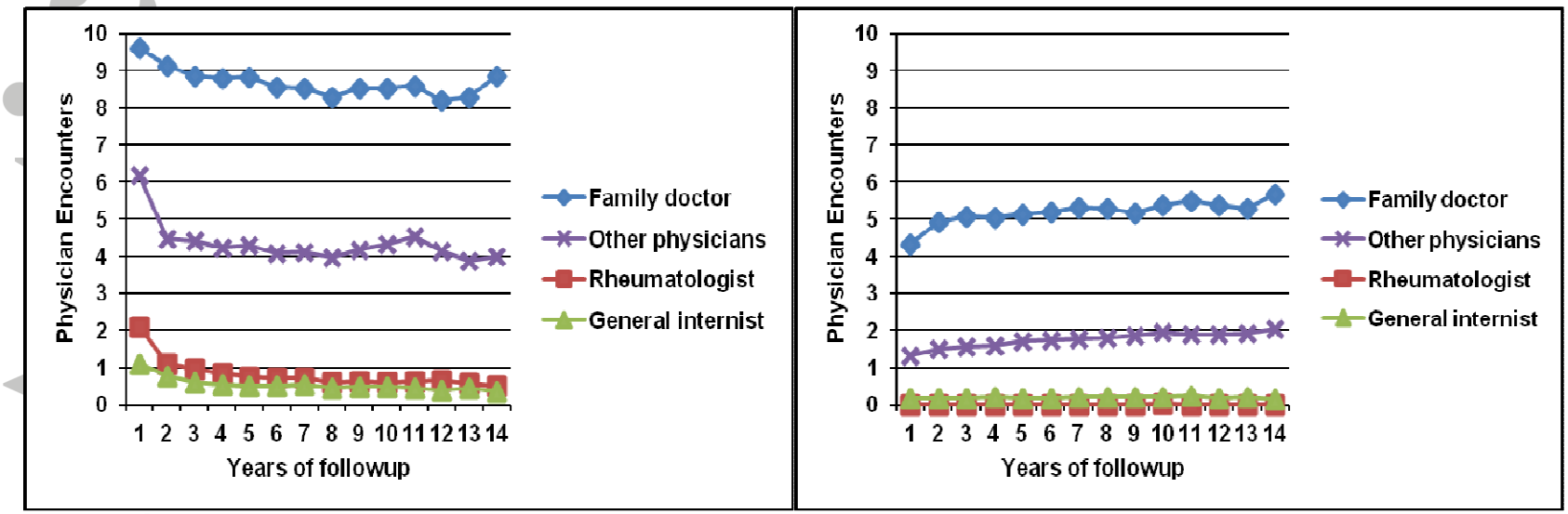
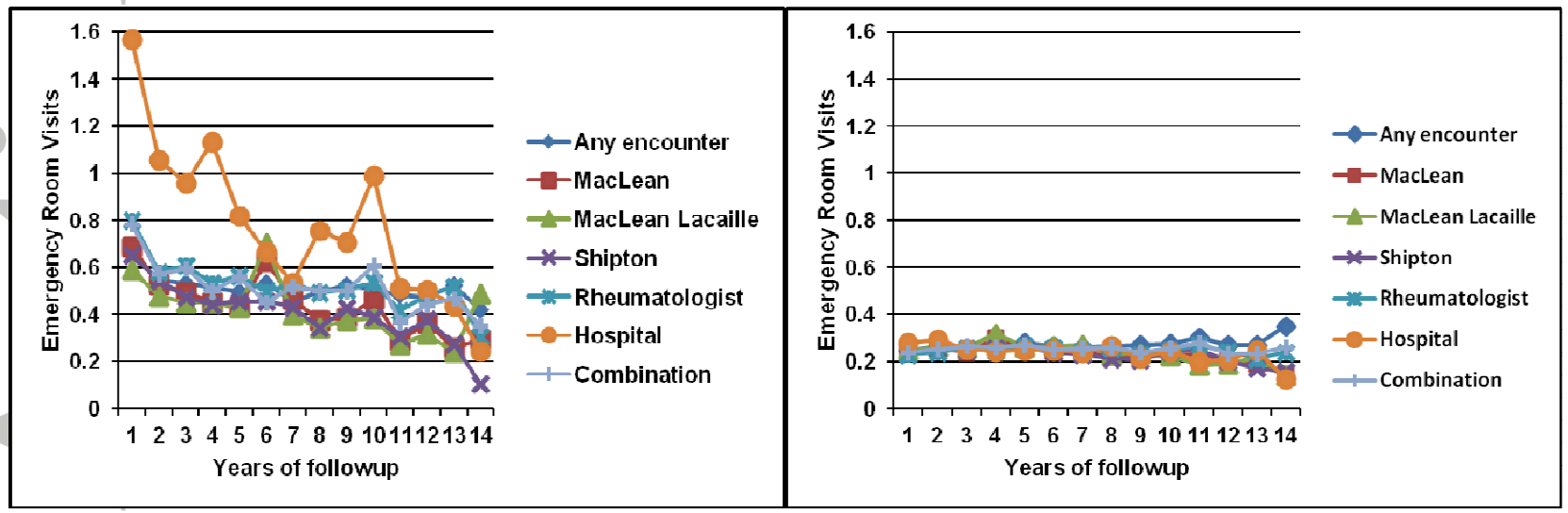


Figure 3:



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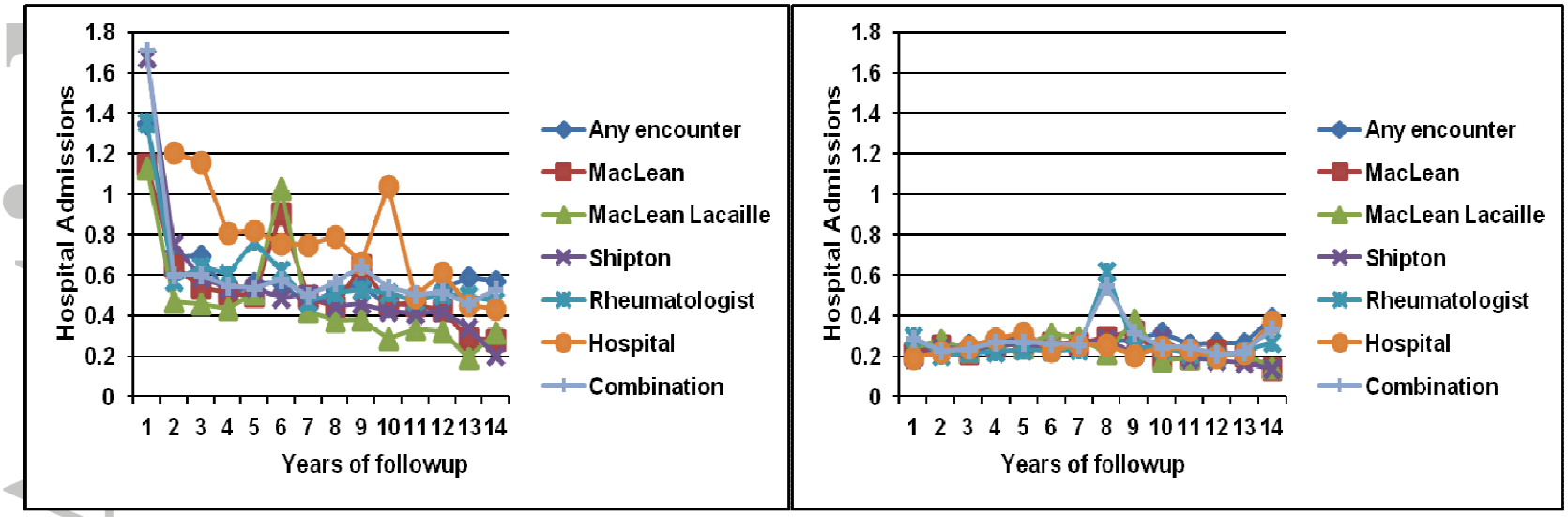

Legends for figures:

Figure 1: Total physician encounters in SLE patients (left panel) and controls (right panel) in the index year and over the following 13 years using 7 definitions for SLE to identify cases in administrative datasets. SLE cases were matched one to four by age and gender to a control cohort of patients who were enrolled in the same datasets but without a diagnosis of SLE or other connective tissue diseases.

Figure 2: Physician encounters by specialty group in SLE patients (left panel) in the index year and over 13 years of followup using case definition #7 (Combination) to identify SLE cases. These were matched one to four by age and gender to a control cohort of patients (right panel) who were enrolled in the same datasets but without a diagnosis of SLE or other connective tissue diseases.

Figure 3: Utilization of the emergency room by SLE cases (left panel) and controls (right panel) in the index year and over the following 13 years using 7 definitions for SLE to identify cases in administrative datasets. SLE cases were matched one to four by age and gender to a control cohort of patients who were enrolled in the same datasets but without a diagnosis of SLE or other connective tissue diseases.

Figure 4: Hospital admission rates in SLE cases (left panel) and controls (right panel) in the index year and over the following 13 years using 7 definitions for SLE to identify

cases in administrative datasets. SLE cases were matched one to four by age and gender to a control cohort of patients who were enrolled in the same datasets but without a diagnosis of SLE or other connective tissue diseases. For patients identified through a hospital admission associated with SLE (case definition #5) the data point for the admission rate at the first encounter was 7.23 and was not included in the graph

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