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Patterns of Health Care Utilization and Medication Adherence Among Youth with Systemic Lupus Erythematosus During Transfer from Pediatric to Adult Care

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Abstract

Objectives: Youth with systemic lupus erythematosus (SLE) transferring from pediatric to adult care are at risk for poor outcomes. We describe patterns of rheumatology/nephrology care and changes in health care utilization and medication adherence during transfer.

Methods: We identified youth ages 15–25 with SLE using US private insurance claims from Optum's de-identified Clinformatics® Data Mart. Rheumatology/nephrology visit patterns were categorized as 1) unilateral transfers to adult care within 12 months, 2) overlapping pediatric and adult visits, 3) lost to follow-up, or 4) continuing pediatric care. We used negative binomial regression and paired t-tests to estimate changes in health care utilization and medication possession ratios (MPR) after the last pediatric (index) visit. We compared MPRs between youth who transferred and age-matched peers continuing pediatric care.

Results: 184 youth transferred out of pediatric care, of which 41.8% transferred unilaterally, 31.5% had overlapping visits over a median of 12 months before final transfer, and 26.6% were lost to follow-up. We matched 107 youth continuing pediatric care. Overall ambulatory utilization decreased among those lost to follow-up. Acute care utilization decreased across all groups. MPRs after the index date were lower in youth lost to follow-up (mean 0.24) compared to peers in pediatric care (0.57, $p<0.001$).

Conclusion: Youth with SLE with continuous private insurance coverage do not use more acute care after transfer to adult care. However, a substantial proportion fail to see adult subspecialists

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within 12 months and have worse medication adherence, placing them at higher risk for adverse outcomes.

Introduction

Pediatric-onset systemic lupus erythematosus (pSLE) is a life-long autoimmune condition with a high health care burden and greater risk of mortality and organ damage compared to adult-onset disease (1–3). Youth with pSLE may be particularly vulnerable when transferring care from pediatric to adult health systems. Previous studies have demonstrated higher in-hospital mortality and hospital readmission rates among transition-age youth with SLE compared to children or older adults with SLE (4,5). These findings are potentially mediated by gaps in care and medications during transfer to adult care (6,7).

Although transfer to adult care has been linked to worse outcomes in other chronic pediatric conditions such as sickle cell disease and juvenile-onset diabetes (8,9), there are very few studies on transfer outcomes among young adults with pSLE. Furthermore, there is a relative paucity of literature regarding the third and final phase of transition, when young adults begin engaging with adult health care systems (10). Timeliness of the first visit to adult care after discharge from pediatric care is a key indicator of successful transfer (11). However, it remains challenging to quantify or assess the impact of gaps in care among geographically mobile young adults due to challenges linking data between pediatric and adult health care systems. Consequently, prior studies of transition outcomes among youth with pSLE have focused on transfers from or to a single-center institution (12–14). As practice-based transition models range from no systematic approach to dedicated adolescent clinics and combined pediatric/adult transition clinics (10,15,16), population-based studies can better approximate what occurs in real-world settings.

Administrative data present a unique opportunity to evaluate patterns of transfer at a national level. In addition, relevant outcomes of transfer such as ED visits, hospitalizations, frequency of ambulatory care and medication prescription fills are well-captured. Therefore, the objectives of this study were to: 1) describe patterns of transfer from pediatric to adult rheumatology/nephrology in youth with pSLE, 2) compare health care utilization before and after the last pediatric subspecialty visit, and 3) compare rates of medication adherence by subspecialty transfer pattern. We hypothesized that youth who fail to see an adult subspecialist within 12 months of the last pediatric visit would have decreases in overall ambulatory care use and increases in acute care use, as well as lower medication adherence than those with timely transfers to an adult provider.

Patients and Methods

Study Population

We identified SLE cases with ≥ 12 months of continuous enrollment at age 15–25 years in Optum's de-identified Clinformatics ® Data Mart Database, which is derived from a national, commercial health insurer covering approximately 20% of US residents from 2000 to 2016. The database contains de-identified patient-level demographics, billable health care encounters, encounter-level diagnosis and procedure codes, and prescription drug fills.

Pediatric and adult subspecialties are defined by provider category codes. As reimbursement is tied to claims, utilization is well-captured.

SLE was defined by the presence of ≥ 3 ICD-9-CM (710.0) or ICD-10-CM (M32.1x, M32.8, M32.9) diagnosis codes for SLE, each at least 30 days apart (17,18). SLE cases were required to have ≥ 1 physician claim from a nephrologist or rheumatologist. Youth remaining exclusively in pediatric rheumatology/nephrology care throughout enrollment were randomly sampled with replacement and frequency matched by age with youth who transferred to adult care or were lost to follow-up. Due to the de-identified nature of the dataset, an exemption was approved for this study by the Institutional Review Boards of the Children's Hospital of Philadelphia and the University of California San Francisco (18–25472), which means written consent and approval by a research ethics board were not required.

Study Measures

Successful transfers were defined by the occurrence of an adult rheumatology/nephrology visit within 12 months after the last pediatric subspecialist visit. Youth were categorized by pattern of rheumatology and nephrology subspecialty care as follows: 1) successful unilateral transfer from a pediatric to adult subspecialist, 2) successful transfer with overlapping pediatric and adult visits preceding final transfer to adult care (with < 12 months between the last pediatric and subsequent adult visit), 3) lost to follow-up (> 12 months between the last pediatric visit and first adult visit or end of enrollment), or 4) continuing pediatric care throughout enrollment without seeing an adult subspecialist (Figure 1). As a descriptive reference we also characterized a fifth group that received only adult care. For youth in each of the three transfer groups, the last pediatric visit during enrollment was considered the index date (Figure 2). For those continuing pediatric care, the index date was the age-matched pediatric visit. A minimum of 6 months of eligibility before and after the index date were required for inclusion. By definition, those categorized as lost to follow-up had ≥ 12 months of eligibility after the index date.

The primary health care utilization outcomes were the rate of all ambulatory encounters (primary and specialty care) and acute care encounters (emergency/urgent care visits and hospitalizations) in the year following the index date. Medication adherence among prevalent hydroxychloroquine users was estimated using prescription fill data to calculate hydroxychloroquine medication possession ratios (MPR), defined as the number of days supply over total observation days in the year following the index date (excluding hospital days from numerator and denominator). Prevalent use was defined by the presence of ≥ 1 hydroxychloroquine prescription fill preceding the index date.

Covariates of interest included demographic characteristics (age at index date, sex, race/ethnicity, geographic region, highest household education), disease characteristics preceding the index date as proxies for disease severity (nephritis, dialysis/transplant, central nervous system involvement defined by seizure or stroke, psychiatric diagnosis, as previously described) (19), as well as baseline MPRs and ambulatory/acute care use in the year preceding the index date. Time between the first adult and last pediatric visit was assessed in youth with overlapping care.

Statistical Analysis

Demographics, disease characteristics and baseline utilization rates were assessed using standard descriptive statistics and compared across transfer groups using Chi-square tests for categorical variables and Kruskall Wallis tests for continuous variables. Multinomial logistic regression was used to identify baseline characteristics independently associated with each transfer group. Differences between transfer groups were tested using likelihood ratio tests.

Negative binomial regression was used to estimate incidence rate ratios (IRR) comparing utilization rates during the observation period to baseline utilization. MPRs before and after the index date were compared within transfer groups using paired t-tests. Two-sample t-tests were used to compare MPRs in each transfer group to age-matched peers continuing pediatric care.

We performed several sensitivity analyses. To address potential ascertainment bias in IRR and MPR estimates, we limited the sample to subjects with at least one encounter or prescription fill during the observation period. To address asynchronous transfers by subspecialty, we re-ran the multinomial logistic regression analysis in those with observation periods defined using pediatric and adult providers within the same subspecialty (rheumatology or nephrology).

Results

Transfer Patterns and Baseline Characteristics

We identified 184 youth who transferred out of pediatric subspecialty care, of which 77 (41.8%) transferred unilaterally to adult care within a year, 58 (31.5%) had successful overlapping transfers, and 49 (26.6%) were lost to follow-up. Of the 226 youth remaining in pediatric care, 107 were age-matched to the transfer groups using the index date. Among the youth who transferred, 18% were Black/African American, 11% were Hispanic, and 7% were Asian. Baseline characteristics were well-balanced between youth in each transfer group and their age-matched peers in pediatric care, save for longer eligibility after the index visit and fewer minorities in the lost to follow-up group (Supplemental Table 1). There was also an increased proportion of youth from the Midwest with overlapping successful transfers compared to pediatric matches (29% vs. 16%, p-value 0.03).

The mean age at the index date was 18.4 (SD 2.1). On average, youth with successful unilateral transfers to adult care were older at the index date than those with successful overlapping transfers or lost to follow-up (mean age 19.4 vs. 18.7 and 18.5, respectively, p-value 0.02) (Table 1). Median time between the index date and first adult visit was 99 days (IQR 50 – 225) among unilateral transfers, compared to 577 days (IQR 453 – 936) among youth lost to follow-up who saw an adult subspecialist before the end of enrollment (n=34). In youth with successful overlapping transfers, the median period of overlap between the first adult and last pediatric visit was 12 months (IQR 4 – 27), and the median time from the index date to the next adult visit was 35 days (IQR 12 – 96). Of note, 21 (43%) patients who were lost to follow-up also had one or more adult subspecialty visits before the index date with a median overlap of 22 months (IQR 8 – 37).

Among 120 youth whose index visit was with pediatric rheumatology, the majority of transfers were to adult rheumatology (96%, 86%, and 96% in the unilateral transfer, overlapping transfer, and lost-to-follow-up groups, respectively). Among the 58 subjects whose index visit was with pediatric nephrology, 11/20 (55%) unilateral transfers were to adult nephrology, compared to 2/21 (10%) of overlapping transfers and 4/17 (24%) of those lost-to-follow up. The remainder of transfers were to adult rheumatology.

Predictors of Subspecialty Transfer Pattern

Age at index date, geographic region, and baseline ambulatory care utilization rates were independently associated with transfer pattern (Supplemental Table 2). Each one year increase in age at the index visit was associated with a significantly lower likelihood of successful overlapping transfer or being lost to follow-up relative to unilateral transfer (relative risk ratio (RRR) 0.82, p-value 0.04 and 0.80, p-value 0.03, respectively). In contrast, living in the Midwest instead of the Northeast was independently associated with a greater than 5-fold increased risk of being lost to follow-up relative to unilateral transfer (RRR 5.52, p-value 0.03). The relative risk of overlapping instead of unilateral successful transfers was higher in the Midwest compared to both the Northeast (RRR 7.96, p-value < 0.01) and the South (RRR 5.22, p-value < 0.01). Higher baseline ambulatory care utilization was associated with overlapping transfer, in keeping with how this group was defined (p-value 0.01). Race/ethnicity, sex, and the presence of major organ manifestations or psychiatric diagnoses were not significantly associated with transfer pattern (Supplemental Table 2). Upon restricting the analysis to transfers between pediatric and adult providers within the same subspecialty, we identified the same predictors of transfer pattern.

Health Care Utilization Outcomes

After the index date, ambulatory visit rates decreased by 0.7-fold among youth lost to follow-up or with overlapping successful transfer ($p<0.01$) (Figure 3a), but remained unchanged among those with unilateral transfers or those continuing pediatric care (Table 2). Rates of acute care utilization decreased across all groups, including those continuing pediatric care (IRRs 0.14–0.30, $p<0.01$) (Figure 3b).

Medication Adherence Outcomes

Hydroxychloroquine MPRs were low across all transfer groups, with a mean MPR of 0.40 (SD 0.36) at baseline and 0.42 (SD 0.35) during the observation period. Youth who were lost to follow-up had the lowest MPRs before and after the index date (Figure 4). There was a trend towards a 25% decrease in average MPR after transfer among youth lost to follow-up, albeit not statistically significant (p-value 0.096). In contrast, those remaining in pediatric care had a 33% increase in mean MPR after the index date ($p < 0.001$), and MPRs for unilateral transfers remained unchanged. For reference, peers in the adult care only group with an SLE code before the age of 18 had an average MPR of 0.45 (SD 0.35) at one year of follow-up, which remained stable at 0.44 (SD 0.33) after two years of follow-up.

The mean MPR after the index date was significantly lower in the lost to follow up group compared to age-matched peers remaining in pediatric care ($p_b < 0.001$). There were no

significant differences in post-index date MPRs among unilateral or overlapping successful transfers and peers remaining in pediatric care.

There were only two subjects in the lost to follow-up group that did not have any health care encounters or SLE-related prescription fills during the observation period. Exclusion of these subjects did not significantly change IRR estimates (IRR 0.71 for ambulatory visits, 95% CI [0.54 – 0.94] and 0.14 for acute care, 95% CI [0.04 – 0.43]) or MPRs (mean pre- and post- MPRs 0.33 and 0.25, respectively).

Discussion

In this population-based study of transfer outcomes among youth with SLE in the US, a quarter of youth failed to see an adult rheumatologist or nephrologist within 12 months of their last pediatric subspecialty visit, despite uninterrupted health insurance coverage and relatively high household educational attainment. Those who were lost to follow-up had the lowest ambulatory care use and medication adherence during the observation period. Although gaps in care and decreases in medication adherence did not correspond with short-term increases in acute care utilization, the high risk of morbidity and excess mortality in young adults with SLE underscores the importance of ongoing evaluation of medication adherence and follow-up care in this age group. Our findings highlight the need for coordinated transfer planning as part of the transition process, and can inform improvement strategies by identifying individuals who are most likely to require additional support when transferring from pediatric to adult lupus care.

Seeing an adult provider within an appropriate timeframe has been considered one of the key indicators of successful transition (11,20,21). In addition, a shorter interval between the last pediatric and first adult visit is associated with a higher likelihood of establishing consistent adult care (22). In our study, failure to see an adult subspecialist within 12 months was associated with decreases in rates of overall ambulatory care use and medication adherence. Although maintaining access to health care is critical, our results emphasize that continuous insurance coverage alone will not ensure timely visits to adult care. Similar observations have been made among pediatric rheumatology practices in settings with universal health care models, such as the United Kingdom and Canada (23,24). These findings support the need for systematic approaches to confirm timely transfer completion (25).

We identified several risk factors that can help clinical teams focus interventions and resources on youth with SLE who are most likely to experience prolonged gaps in care. Those with less frequent ambulatory care at baseline were more likely to be lost to follow-up. This has also been observed in primary care settings, in which low transfer completion was associated with difficulties bringing youth back to the pediatrician to facilitate transfer (26). Population management strategies to monitor high-risk patients and ensure frequent visits during transfer planning remain an important opportunity area. Other risk factors for untimely transfers included geographic region, which could reflect regional rheumatology workforce shortages (27). Regional variation in health outcomes can also suggest opportunities for standardization, though more granular data are needed to direct improvement efforts (28). Lastly, older age was a determinant of successful unilateral

transfer, which is consistent with findings in other chronic conditions and may relate to differences in levels of social and emotional maturation (29). There has been significant attention towards assessment of transition readiness, which more specifically identifies skills and behaviors needed for health care independence than chronologic age (25,30). However, transitions readiness scores from existing tools have yet to be correlated with better transfer outcomes (31). Additional predictors of transfer success, including baseline health care utilization, access issues and socioeconomic factors, will be important to consider in addition to transition readiness when determining the right age for transfer to adult care.

Various periods of overlapping pediatric and adult care were common and not explained by asynchronous rheumatology/nephrology transfers. Changes in ambulatory care utilization are difficult to assess in this group, as decreased visits after discharge from pediatric care was partly a consequence of how the group was defined. Differences in presence and duration of overlap likely reflect variation in transitional practice models (32). Meeting adult providers before transfer is associated with better transition outcomes in other chronic diseases (33), and “transition clinics” where adult rheumatologists see patients with the pediatric team have been described (16). However, experience suggests young adults may return to pediatric care due to negative experiences in adult-centered care (34). In our study, overlapping care occurred with the same frequency in successful and unsuccessful transfers, therefore the reasons for overlap (i.e. practice vs. patient-driven) may be more important determinants of success. The observed regional differences despite similar rates of major organ involvement suggest practice norms likely contribute to overlap, however there were no practice-level indicators to assess preferencebased drivers. Further research is needed to understand reasons for and impact of overlapping care.

Medication adherence is another component to key indicators of successful transition, including self-management and maintenance of disease control (35). In our study, baseline levels of adherence to hydroxychloroquine were low across the entire cohort. Adherence became significantly lower in those lost to follow-up compared to age-matched peers remaining in pediatric care, while adherence remained stable among youth with timely unilateral or overlapping transfers. In the juvenile diabetes literature, transfer was associated with worse glycemic control compared to remaining in pediatric care (9), however our results suggest that timely transfers may be protective in pSLE. Low overall adherence rates in pSLE may be due to a combination of factors, including concerns about side effects, direct effects of SLE on neurocognition, mood disorders (36), poor adaptation/coping with illness (37), and delayed maturation of self-management skills due to onset of chronic illness in childhood, including deficits in ordering prescription refills (6,38–40). In addition, prolonged gaps in care during transfer can result in lapses in prescription supply, so clinical teams should ensure that primary prescribers are clearly delineated during transfer. Previous studies have demonstrated that damage accrual from pSLE continues through adulthood (41,42), and onset of SLE in childhood is an independent predictor of excess mortality in young adults with SLE, emphasizing the importance of ongoing evaluation of medication adherence (3).

Contrary to our initial hypothesis, one somewhat reassuring finding from our study was that acute care utilization decreased during transfer to adult lupus care among youth with

uninterrupted insurance coverage. There are several potential explanations. First, pediatric subspecialists may wait to transfer patients with SLE during periods of disease stability, particularly if formal transfer planning processes have been implemented (13,43). Secondly, acute care utilization among patients with SLE has been shown to decline with disease duration, which could drive our results (44). Third, a decreased frequency of overall acute care encounters may be driven by a reduction in scheduled hospitalizations for infusions after transfer to adult care, as demonstrated in one academic center (13). Lastly, our observation period was relatively short, so it is possible that a longer latency period following transfer is needed to observe increased acute care utilization as an effect of prolonged gaps in care or medication nonadherence. Adolescents with other chronic conditions also demonstrate relative stability of short-term patterns of health care use during transfer to adult care (45), but data on long-term patterns of acute care use are needed.

There are several strengths to our study. To our knowledge, this is the largest and only population-based study of transfer outcomes among youth with pSLE in the US. More importantly, we were able to measure outcomes across health care institutions and state lines. We also identified several important factors associated with becoming lost to follow-up that can guide targeted interventions when resources to support transition are more limited, as is often the case. There were also several limitations to our approach. First, we were unable to assess disease activity or psychosocial factors, which are important individual-level determinants of health care use. Secondly, we were unable to assess the impact of gaps in insurance coverage, which affects up to one-third of pSLE patients transferring to adult care (12). Lastly, our results need to be interpreted in the context of commercial insurance enrollees, which underrepresent minorities and families with lower socioeconomic status. Only 18% of our cohort was Black/African American, compared to 34% in a national registry and 40% in Medicaid enrollees (18,46). Racial and socioeconomic disparities exist in both disease severity and outcomes (36,47,48), and therefore our findings have limited generalizability to publicly insured or uninsured individuals who are at higher risk for poor outcomes (49,50). Transition outcomes research in Medicaid enrollees poses separate methodologic challenges from loss of eligibility upon reaching adulthood, and it remains an important area for further study.

In conclusion, access to continuous insurance coverage is necessary but not sufficient to ensure successful transfer to adult care among young adults with SLE. Transition interventions and resources should be targeted toward youth who are at the highest risk for being lost to follow-up after discharge from pediatric subspecialty clinics. Particular attention is needed to ensure adequate ambulatory follow-up care and medication adherence during transition and confirm transfer completion. Adult lupus subspecialists should consider routine assessment of medication adherence in recently transferred young adults. Our study highlights the need for future research to include outcome assessment during the third phase of transition. Additional data are needed to determine whether interventions targeting health care utilization and medication adherence patterns during transfer improve longitudinal health outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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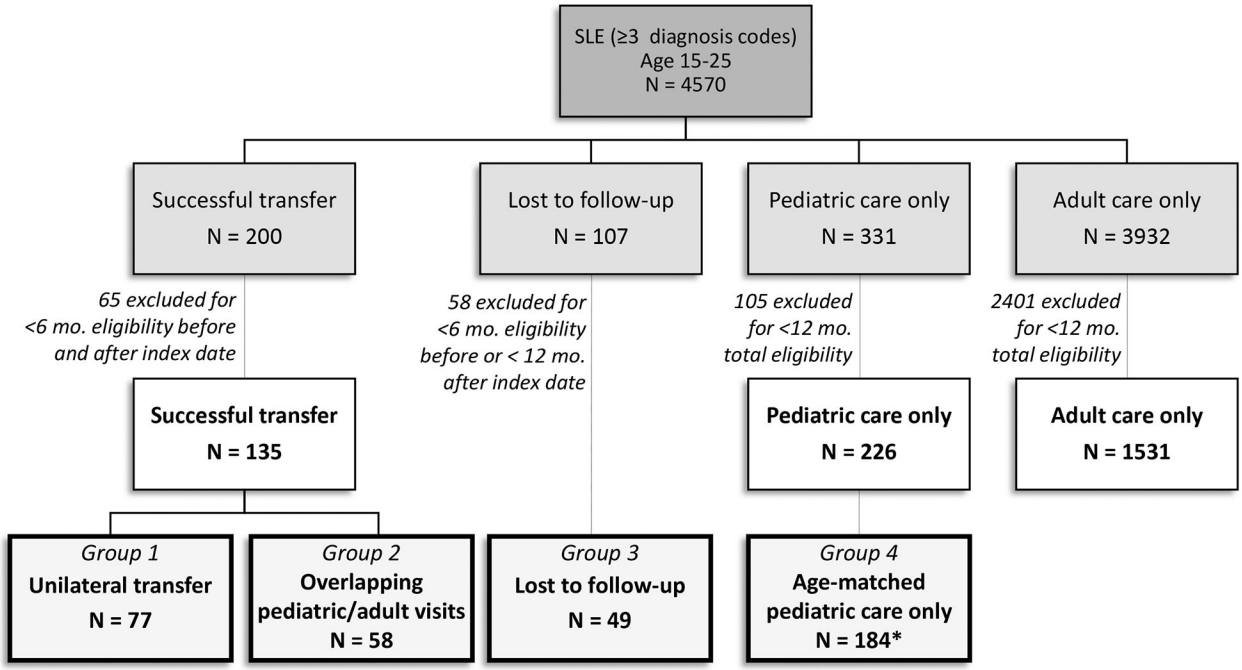

Figure 1.

Categorization of ambulatory rheumatology and nephrology health care utilization patterns among transition-age youth with SLE. Successful transfer of care was defined as < 12 months between the last pediatric visit and the first adult visit during the eligibility period.

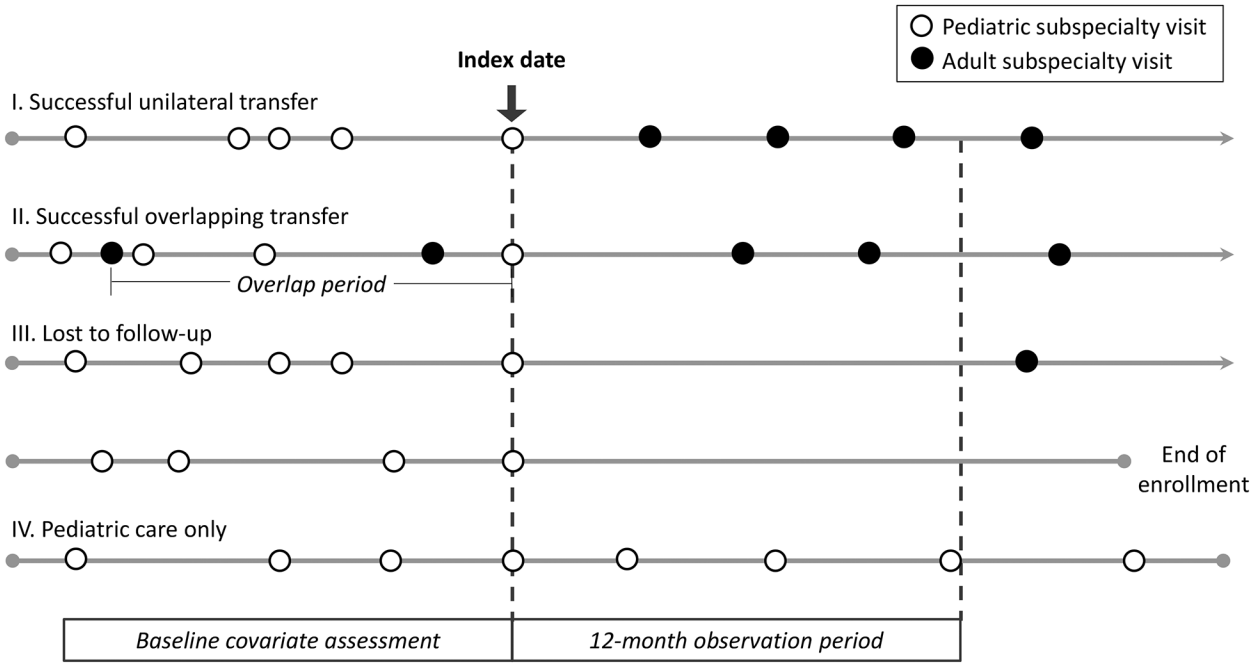

Figure 2.

Categorization of lupus subspecialty transfer patterns and age-matched peers continuing pediatric care. Outcomes were assessed during the observation period up to 12 months after the index date.

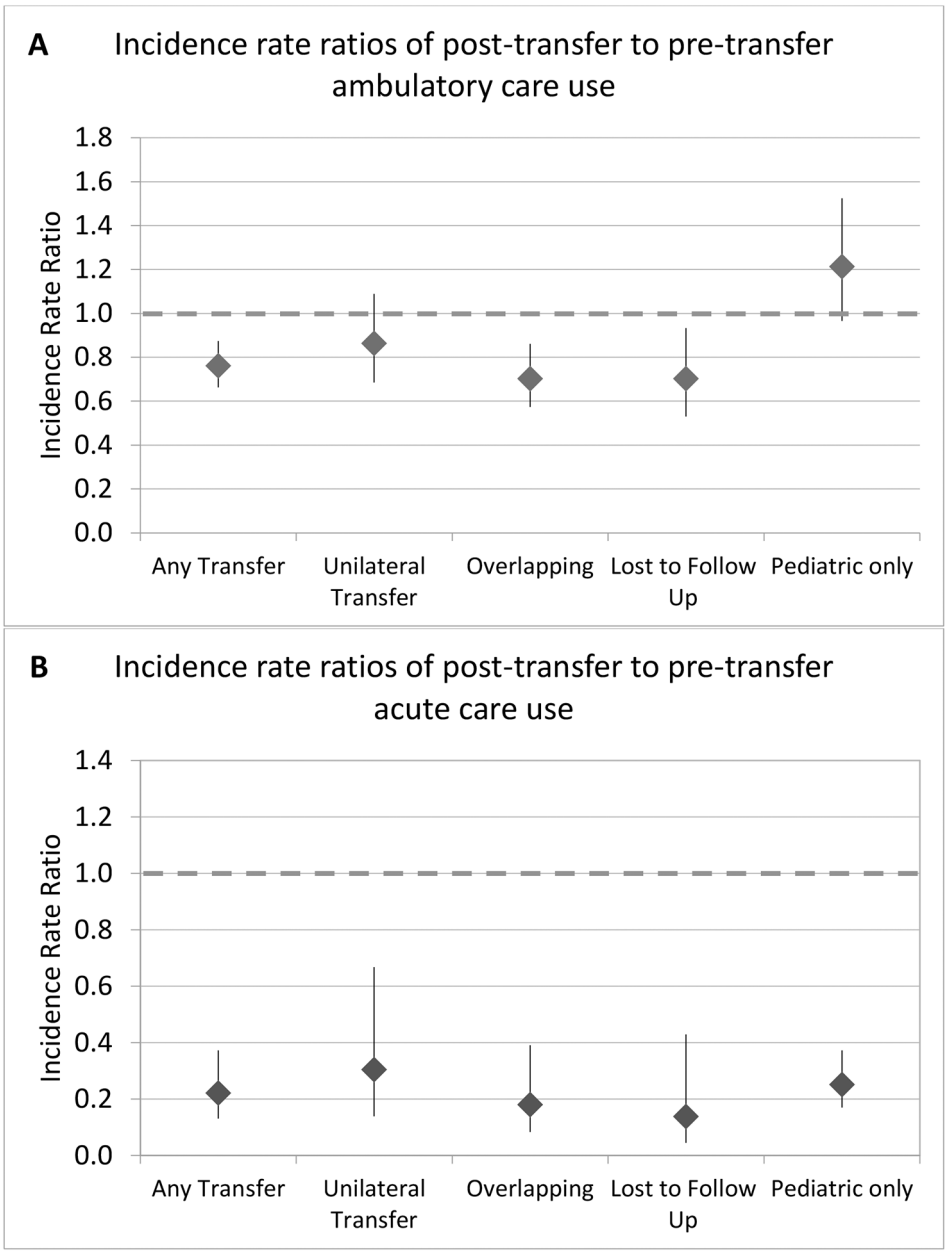

Figure 3.

A) Incidence rate ratios representing within-group comparisons of post-transfer to pre-transfer rates of ambulatory care use**. B)** Incidence rate ratios representing within-group comparisons of post-transfer to pre-transfer rates of acute care use, including emergency department visits and hospitalizations.

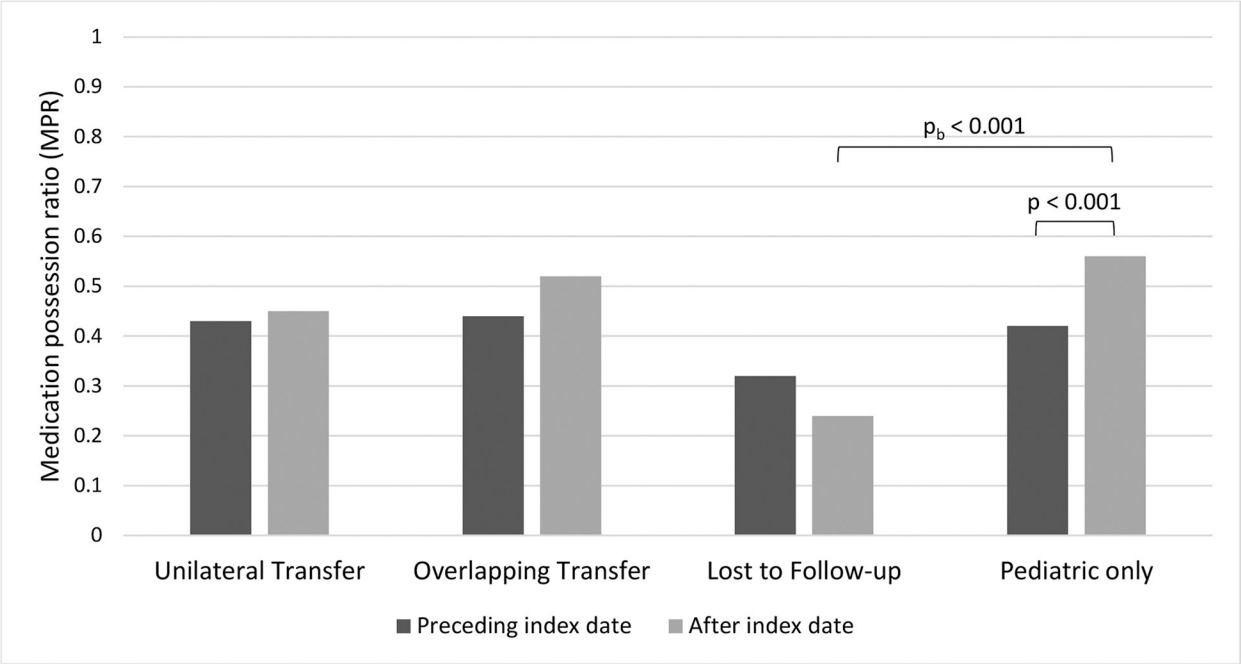

Figure 4.

Comparison of average medication possession ratios (MPR) one year before and after transfer using paired t-tests. Between-group differences were tested using two-sample t-tests, of which statistically significant differences are also shown (p_b).

Table 1.

Baseline Characteristics by Transfer Group

	Successful Unilateral Transfer (N=77)	Successful Overlapping Transfer (N=58)	Lost to Follow-up (N=49)	p*	Pediatric only (N=184)†
Age at index date,‡ mean (SD)	19.4 (±2.0)	18.7 (±2.1)	18.5 (±2.2)	0.02	18.4 (±2.1)
Eligibility,§ median yrs [IQR]	2.4 [1.1–4.0]	1.9 [1.0–3.5]	3.6 [1.5–4.8]	0.05	1.9 [1.0–3.0]
Female sex, n (%)	67 (87%)	51 (88%)	45 (92%)	0.70	148 (80%)
Race/Ethnicity					
White	46 (61%)	37 (65%)	29 (64%)	0.78	84 (50%)
Black	13 (17%)	10 (18%)	10 (22%)		33 (20%)
Hispanic	10 (13%)	5 (9%)	5 (11%)		39 (23%)
Asian/Other	7 (9%)	5 (9%)	1 (2%)		13 (8%)
Highest household education					
≤ High school diploma	20 (26%)	12 (21%)	9 (19%)	0.60	53 (31%)
Some higher education	57 (74%)	46 (79%)	39 (80%)		121 (66%)
Region					
Midwest	8 (10%)	17 (29%)	9 (18%)	0.04	32 (17%)
Northeast	17 (22%)	6 (10%)	4 (8%)		39 (21%)
South	38 (49%)	23 (40%)	27 (55%)		92 (50%)
West	14 (18%)	12 (21%)	9 (18%)		21 (11%)
Disease characteristics preceding index date:					
All ambulatory visits/yr, median [IQR]	7[4–16]	11 [7–26]	6 [2–10]	<0.01	7 [4–15]
Acute care visits/yr	0 [0–1]	0 [0–3]	0 [0–0]	0.34	0 [0–0]
Seizures, n (%)	9 (12%)	7 (12%)	5 (10%)	0.95	12 (7%)
Stroke	3 (4%)	4 (7%)	1 (2%)	0.46	7 (4%)
Nephritis	31 (40%)	26 (45%)	19 (39%)	0.79	65 (35%)
Dialysis	2 (3%)	3 (5%)	1 (2%)	0.60	2 (1%)
History of renal transplant	1 (1%)	3 (5%)	3 (6%)	0.31	6 (3%)
Psychiatric diagnosis	27 (35%)	20 (34%)	11 (22%)	0.28	25 (14%)

*Pearson chi-square or Kruskal Wallis test comparing three transfer groups

†representing 107 unique patients (sampled with replacement)

‡Date of last pediatric visit for transfer groups; matched visit date for group remaining in pediatric care

§Years of continuous insurance eligibility after the index date

Table 2.

Health care utilization during transfer period compared to pre-transfer

	IRR*	95% CI	p-value
	All ambulatory care visits		
Any Transfer	0.76	[0.66, 0.87]	<0.01
Successful Unilateral Transfer	0.86	[0.69, 1.09]	0.22
Successful Overlapping Transfer	0.70	[0.57, 0.86]	<0.01
Lost to Follow Up	0.70	[0.53, 0.93]	0.02
Pediatric only	1.21	[0.97, 1.52]	0.10
	Acute care visits		
Any Transfer	0.22	[0.13, 0.37]	<0.01
Successful Unilateral Transfer	0.30	[0.14, 0.67]	<0.01
Successful Overlapping Transfer	0.18	[0.08, 0.39]	<0.01
Lost to Follow Up	0.14	[0.04, 0.43]	<0.01
Pediatric only	0.25	[0.17, 0.37]	<0.01

*Incidence rate ratios for each transfer group estimated from negative binomial regression models of health care visits during the observation period compared to baseline period, clustered by subject