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Patterns of Healthcare Use and Medication Adherence among Youth with Systemic Lupus Erythematosus during Transfer from Pediatric to Adult Care

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ABSTRACT. ***Objective.*** 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 healthcare use and medication adherence during transfer.

Methods. We identified youth ages 15–25 with SLE using US private insurance claims from Optum's deidentified 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 followup, or (4) continuing pediatric care. We used negative binomial regression and paired t tests to estimate changes in healthcare use and medication possession ratios (MPR) after the last pediatric (index) visit. We compared MPR between youth who transferred and age-matched peers continuing pediatric care.

Results. Of the 184 youth transferred out of pediatric care, 41.8% transferred unilaterally, 31.5% had overlapping visits over a median of 12 months before final transfer, and 26.6% were lost to followup. We matched 107 youth continuing pediatric care. Overall, ambulatory care use decreased among those lost to followup. Acute care use decreased across all groups. MPR after the index date were lower in youth lost to followup (mean 0.24) compared to peers in pediatric care (mean 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 within 12 months and have worse medication adherence, placing them at higher risk for adverse outcomes.

Key Indexing Terms: pediatric systemic lupus erythematosus, longitudinal studies, outcome assessment, patient compliance, epidemiology

Pediatric-onset systemic lupus erythematosus (pSLE) is a lifelong autoimmune condition with a high healthcare burden and greater risk of mortality and organ damage compared to adult-onset disease[1,2,3]. 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].

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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. Further, there is a relative paucity of literature regarding the third and final phase of transition, when young adults begin engaging with adult healthcare 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 effect of gaps in care among geographically mobile young adults because of challenges linking data between pediatric and adult healthcare systems. Consequently, prior studies of transition outcomes among youth with pSLE have focused on transfers from or to a single-center institution[12,13,14]. Since 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 emergency department visits, hospitalizations, frequency of ambulatory care, and medication prescription fills are well identified. 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 healthcare use 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.

MATERIALS 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 about 20% of US residents from 2000 to 2016. The database contains deidentified patient-level demographics, billable healthcare encounters, encounter-level diagnosis and procedure codes, and prescription drug fills. Pediatric and adult subspecialties are defined by provider category codes. Because reimbursement is tied to claims, use is well recorded.

SLE was defined by the presence of ≥ 3 International Classification of Diseases-9-Clinical Modification (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 followup. Because of the deidentified feature of the dataset, an exemption was approved for our 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 mo between the last pediatric and subsequent adult visit), (3) lost to followup (> 12 mo 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 3 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 followup had ≥ 12 months of eligibility after the index date.

The primary healthcare use 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 (HCQ) users was estimated using prescription fill data to calculate HCQ 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 HCQ 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 MPR 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 use rates were assessed using standard descriptive statistics and compared across transfer groups using chi-square tests for categorical variables and Kruskal-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 use rates during the observation period to baseline use. MPR before and after the index date were compared within transfer groups using paired t tests. Two-sample t tests were used to compare MPR 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 1 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 whom 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 followup. 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% (33/184) were black, 11% (20/184) were Hispanic, and 7% (13/184) 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 group lost to followup (Supplementary Table 1, available with the online version of this article). There was also an increased proportion of youth from the Midwest with overlapping successful transfers compared to pediatric matches (29% vs 16%, p = 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 those lost to followup (mean age 19.4 yrs vs 18.7 and 18.5, respectively, p = 0.02; Table 1). Median time between the index date and first adult visit was 99 days [interquartile range (IQR) 50–225] among unilateral transfers, compared to 577 days (IQR 453–936) among youth lost to followup 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 patients (43%) who were lost to followup also had 1 or more adult subspecialty visits before the index date with a median overlap of 22 months (IQR 8–37).

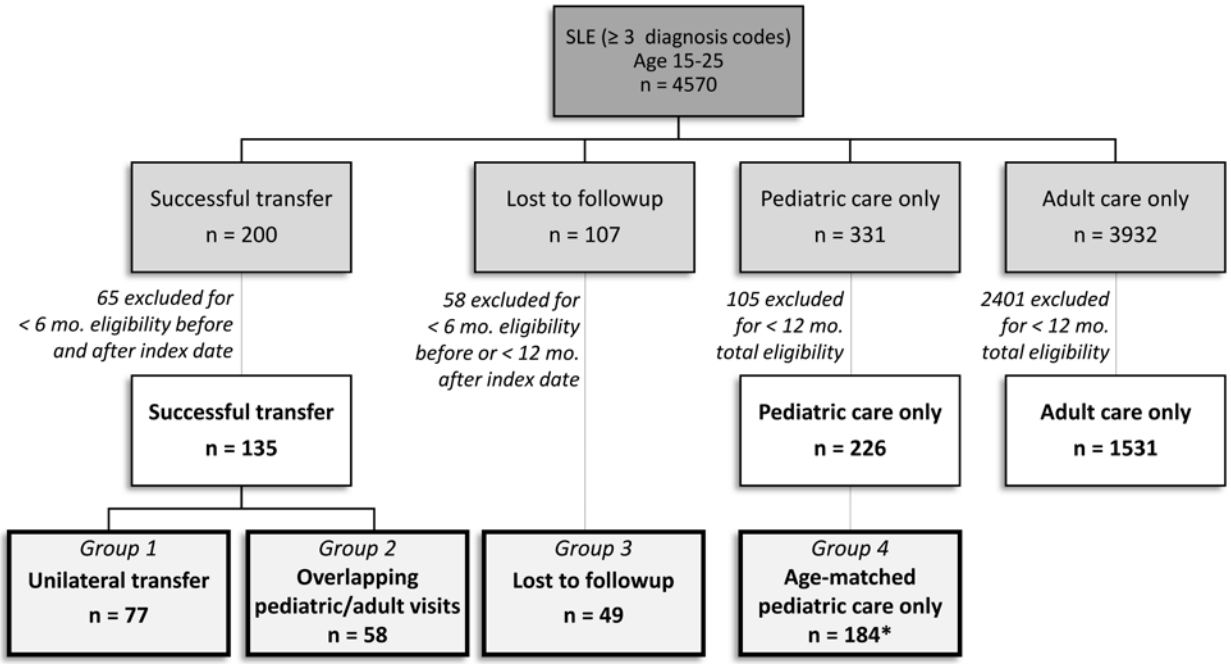

Figure 1. Categorization of ambulatory rheumatology and nephrology healthcare use patterns among transition-age youth with SLE. Successful transfer of care was defined as < 12 months between the last pediatric visit and the first adult visit during the eligibility period. *Sampled with replacement from youth remaining in pediatric care throughout enrollment. SLE: systemic lupus erythematosus.

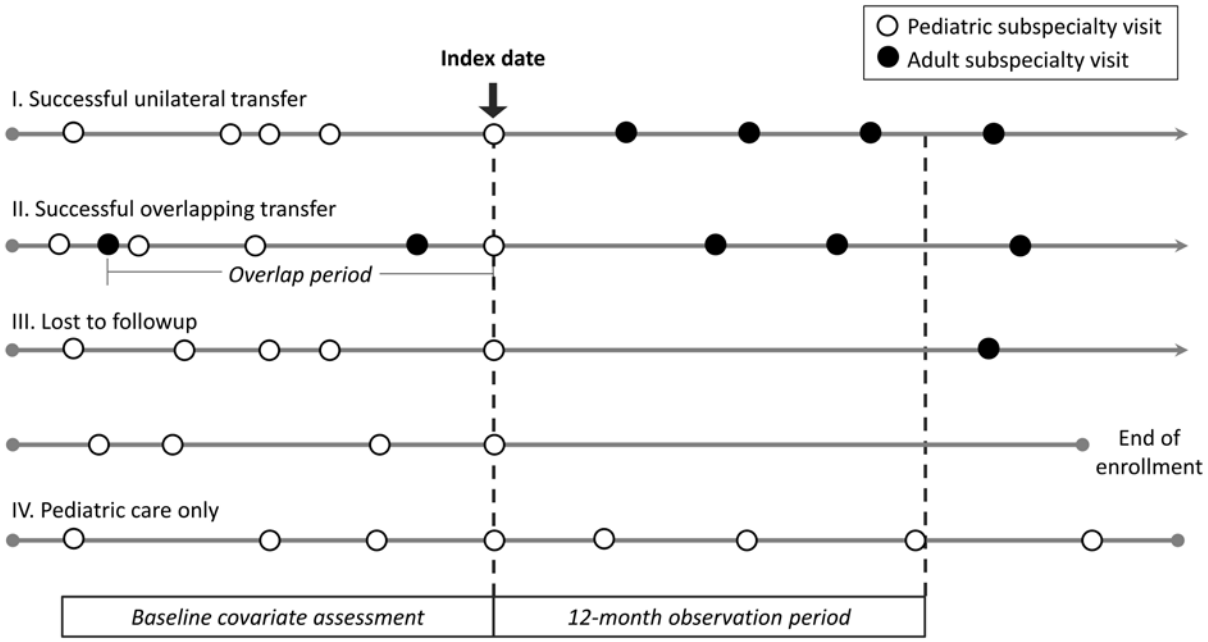

Figure 2. Categorization of systemic lupus erythematosus subspecialty transfer patterns and age-matched peers continuing pediatric care. Outcomes were assessed during the observation period up to 12 months after the index date.

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-followup 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 followup. The remainder of transfers were to adult rheumatology.

Predictors of subspecialty transfer pattern. Age at index date,

Table 1. Baseline characteristics by transfer group.

Characteristics	Successful Unilateral Transfer, n = 77	Successful Overlapping Transfer, n = 58	Lost to Followup, 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, 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 3 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. IQR: interquartile range.

geographic region, and baseline ambulatory care use rates were independently associated with transfer pattern (Supplementary Table 2, available with the online version of this article). Each 1-year increase in age at the index visit was associated with a significantly lower likelihood of belonging to either the successful overlapping transfer group or the lost-to-followup group, relative to the unilateral transfer group [relative risk ratio (RRR) 0.82, p = 0.04 and 0.80, p = 0.03, respectively]. In contrast, living in the Midwest instead of the Northeast was independently associated with a > 5-fold increased risk of being lost to followup relative to unilateral transfer (RRR 5.52, p = 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 < 0.01) and the South (RRR 5.22, p < 0.01). Higher baseline ambulatory care use was associated with overlapping transfer, in keeping with how this group was defined (p = 0.01). Race/ethnicity, sex, and the presence of major organ manifestations or psychiatric diagnoses were not significantly associated with transfer pattern (Supplementary 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.

Healthcare use outcomes. After the index date, ambulatory visit rates decreased by 0.7-fold among youth lost to followup 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 use decreased across all groups, including those continuing pediatric care (IRR 0.14–0.30, p < 0.01; Figure 3B).

Medication adherence outcomes. HCQ MPR 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 followup had the lowest MPR before and after the index date (Figure 4). There was a trend toward a 25% decrease in average MPR after transfer among youth lost to followup, albeit not statistically significant (p = 0.096). In contrast, those remaining in pediatric care had a 33% increase in mean MPR after the index date (p < 0.001), and MPR for unilateral transfers remained unchanged. For reference, peers who received only adult care with an SLE code before the age of 18 had an average MPR of 0.45 (SD 0.35) at 1 year of followup, which remained stable at 0.44 (SD 0.33) after 2 years of followup.

The mean MPR after the index date was significantly lower in the lost-to-followup group compared to age-matched peers

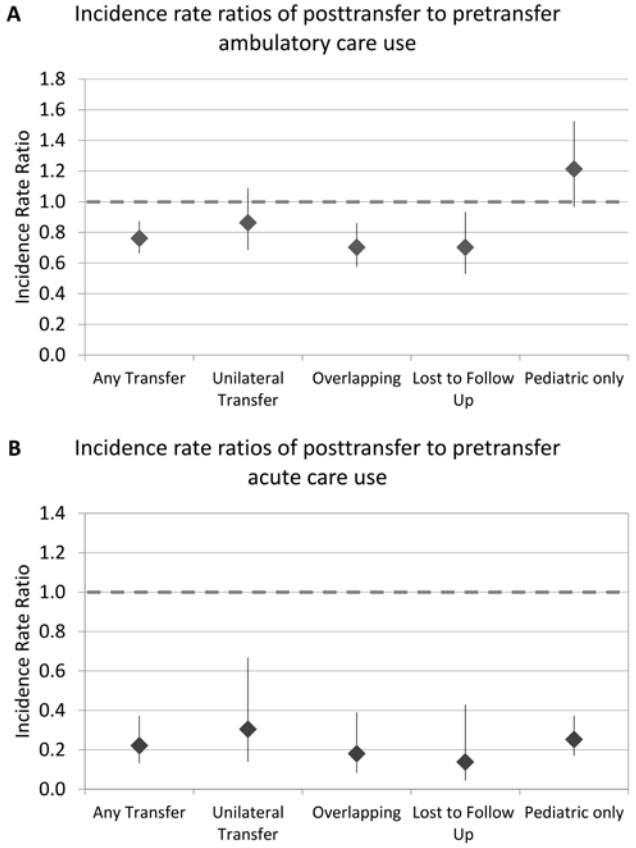

Figure 3. A. Incidence rate ratios representing within-group comparisons of posttransfer to pretransfer rates of ambulatory care use. B. Incidence rate ratios representing within-group comparisons of posttransfer to pretransfer rates of acute care use, including emergency department visits and hospitalizations.

Table 2. Healthcare use during transfer period compared to pretransfer.

Characteristics	IRR*	95% CI	p
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 followup	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 followup	0.14	0.04–0.43	< 0.01
Pediatric only	0.25	0.17–0.37	< 0.01

*Incidence rate ratios (IRR) for each transfer group estimated from negative binomial regression models of healthcare visits during the observation period compared to baseline period, clustered by subject.

remaining in pediatric care (p_b < 0.001). There were no significant differences in postindex date MPR among unilateral or overlapping successful transfers and peers remaining in pediatric care.

There were only 2 subjects in the lost-to-followup group who did not have any healthcare 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 MPR (mean pre- and post-MPR 0.33 and 0.25, respectively).

DISCUSSION

In our population-based study of transfer outcomes among youth with SLE in the United States, 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 followup 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 use, the high risk of morbidity and excess mortality in young adults with SLE underscores the importance of ongoing evaluation of medication adherence and followup 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 SLE 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 healthcare 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 followup. 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 important opportunity areas. Other risk factors for

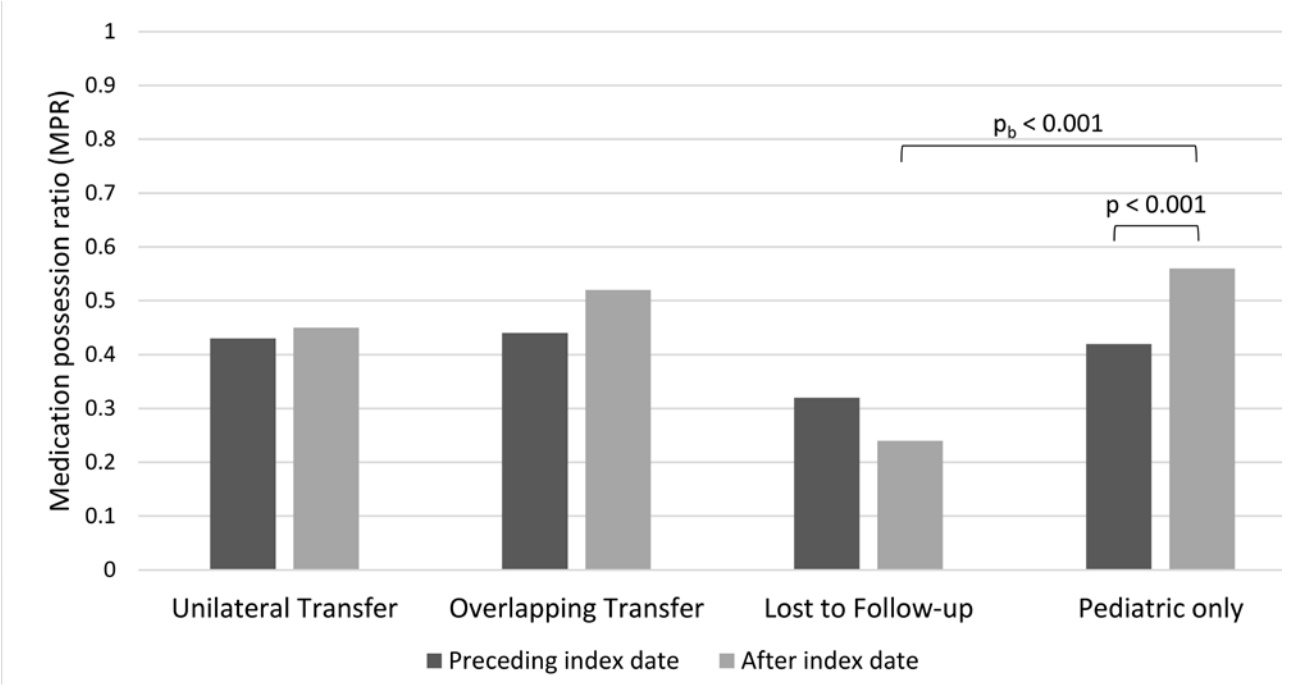

Figure 4. Comparison of average medication possession ratios (MPR) 1 year before and after transfer using paired t tests. Between-group differences were tested using 2-sample t tests; their statistically significant differences are shown (p_b).

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]. Last, 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 toward assessment of transition readiness, which more specifically identifies skills and behaviors needed for healthcare independence than chronologic age[25,30]. However, transition readiness scores from existing tools have yet to be correlated with better transfer outcomes[31]. Additional predictors of transfer success, including baseline healthcare use, 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 use are difficult to assess in this group, because 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 because of 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 preference-based drivers. Further research is needed to understand reasons for and effect 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 HCQ were low across the entire cohort. Adherence became significantly lower in those lost to followup 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 because of onset of chronic illness in childhood, including deficits in ordering prescription refills[6,38,39,40]. 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 use decreased during transfer to adult SLE 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]. Second, acute care use 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 1 academic center[13]. Last, our observation period was relatively short, so it is possible that a longer latency period following transfer is needed to observe increased acute care use 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 healthcare use during transfer to adult care[45], but data on longterm 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 United States. More importantly, we were able to measure outcomes across healthcare institutions and state lines. We also identified several important factors associated with becoming lost to followup 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 healthcare use. Second, we were unable to assess the effect of gaps in insurance coverage, which affect up to one-third of patients with pSLE transferring to adult care[12]. Last, 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 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.

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 followup after discharge from pediatric subspecialty clinics. Particular attention is needed to ensure adequate ambulatory followup care and medication adherence during transition and confirm transfer completion. Adult SLE 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 healthcare use and medication adherence patterns during transfer improve longitudinal health outcomes.

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ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

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Editorial

Transfer from Pediatric to Adult Care Is Hardly Child's Play

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In this issue of *The Journal*, Chang and colleagues describe patterns of rheumatologic/nephrologic care and changes in healthcare use and medication adherence among patients with childhood-onset systemic lupus erythematosus (SLE) during their transfer from pediatric to adult care[1]. The most salient of their findings was a 26% rate of loss to follow-up, defined as more than 12 months between last pediatric visit and first adult visit, or end of enrollment. Consequently, and not surprisingly, ambulatory visits declined (although interestingly, there was no signal for increased acute care use). Medication adherence was poor across groups, regardless of whether the transfer was deemed a "success."

Taken together, Chang, *et al*'s findings reinforce the overarching themes of the literature on pediatric transition to adult care, not to mention the anecdotal — but remarkably consistently held — impressions of physicians who practice in this space: that the period of transition from pediatric to adult care is littered with landmines, quilted with quagmires. Some find their way to adult care and succeed; many others, however, fail dramatically and with dire consequences. Other groups have reported that only 50% of pediatric rheumatology patients transition successfully to adult care[2,3]. Surely, we could forge a less perilous path.

And while patients with childhood-onset SLE, like those in the Chang study, reflect a particularly vulnerable group, with complex and potentially fatal multisystemic disease, the challenges associated with transfer from pediatric to adult care transcend diagnosis or specialty. Themes are consistent among chronic diseases of onset in childhood that persist into adulthood regardless of whether the young patient has SLE, juvenile idiopathic arthritis (JIA), diabetes, or sickle cell disease[4,5,6].

The unique challenges associated with care of these patients are driven by their context. These patients present carrying the physical, psychosocial, and psychic baggage of a chronic disease (whose weight their parents have borne, at least partially) and are now shouldering its bulky burden through the formative experiences that define adolescence. This is a time of differentiation and distancing from parents (sometimes rapidly), progressive independence, moving away from home to attend college or university, experimentation with evolving sexuality, and exposure to drugs and alcohol. Indeed, these formative experiences shape the adults they will become.

For these adolescents with chronic disease, the decision to live away from home must include consideration of the prospect of disease flare and admission to an unfamiliar hospital, far from family. Their decision to live in university residence may affect their ability to manage sleep hygiene, so critical to disease control in many. In others, the intersection between disease process and increased risk associated with oral contraceptives may introduce complex and catastrophic consequences, from unplanned to complicated pregnancies. There is a dizzying array of scenarios wherein disease can affect the experiences, and vice versa.

So how can we collectively catalyze the timely and seamless transition of these young patients into adult care?

1. Pediatric patient preparation.

Patients — nay, humans — fear the unknown. And adult care can reflect the Great Unknown for young adults with SLE and other chronic diseases: patients are now expected to take progressive ownership over illness and its management that, in many cases, was largely managed by parents/caregivers, and to evolve into this role in the uncharted context of adult care. Maddux and colleagues surveyed 370 pediatric patients with inflammatory bowel disease about their perspectives on transition, and found that, among respondents, the most important reasons for unsuccessful transfer, accounting for over half of the responses, were

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comfort with their pediatric doctor and worry about starting over with a new physician[7]. Among this cohort, discussion of the differences between pediatric and adult care was ranked second in importance only to discussion surrounding independent management of their illness and its treatment.

Qualitative interviewing of patients with JIA transitioning to adult care extracted familiarization with the adult clinic as an important factor in allowing the focus to be placed on managing their disease, rather than devoting excess energy to a new setting[8]. Indeed, the simple theme of familiarity with adult care emerges time and time again in transition literature, and could reflect an important opportunity to improve successful coordination of transition, and in doing so, improve outcomes in this vulnerable population[9,10].

With this in mind, perhaps even simple efforts to assuage the patient's fear and anxiety may be of disproportionately high value in promoting successful transition.

2. Provider preparation.

It was nearly 2 decades ago that the American Academy of Pediatrics (AAP) published a consensus statement on healthcare transitions for young adults with special healthcare needs[11]. Its goal was to ensure that, by 2010, "all physicians who provide primary or subspecialty care to young people with special healthcare needs (1) understand the rationale for transition from child-oriented to adult-oriented health care; (2) have the knowledge and skills to facilitate that process; and (3) know if, how, and when transfer of care is indicated." This has driven campaigns like "Got Transition," which serve as resources for physicians, patients, and their parents/caregivers. In spite of these efforts, however, it seems transition from pediatric to adult care is fraught with challenges and considerable risk.

As adult rheumatologists, our assumption was that pediatric rheumatologists' knowledge of and comfort with the transition process were robust. We were thus surprised by the findings of Chira and colleagues, who in 2014 interviewed members of the Childhood Arthritis and Rheumatology Research Alliance, composed mainly of pediatric rheumatologists (for whom transition of patients is an inevitability), and found that fewer than 10% were very familiar with the AAP transition guidelines, and only 8% had a formalized, written transition policy[12].

It is reasonable to assume, then, that adult rheumatologists, whose patients can range in age from 18 years to 118 years, may feel ill-equipped to navigate the challenges of transitioning young adults from pediatric care. Indeed, adult rheumatologists do not typically receive formal training to prepare for the provision of the unique and stage-appropriate care for patients with pediatric-onset disease, which for many, will persist through their adult lives. Matsui and colleagues surveyed adult rheumatologists about issues interfering with transition from pediatric to adult care. They found that, while the vast majority (87%) cared for patients who had transitioned from pediatric care, nearly half reported hesitation and/or anxiety, largely stemming from feeling ill-equipped to address the unique challenges of this patient population[13].

In recent years, European League Against Rheumatism/Paediatric Rheumatology European Society (EULAR/PReS) published standards and recommendations on the provision of transitional care for patients with pediatric-onset rheumatic diseases. Acknowledging that application would present a challenge, they organized these by what was felt to be the bare minimum to support successful transition (i.e., "essential"), and that which reflected optimal care (i.e., "ideal")[14]. This may reflect a fruitful common ground to assist in pediatric and adult collaborations in this important field, and generate new knowledge on the approach to and value of dedicated focus on transfer and transition.

It is critical to identify champions on both the pediatric and adult side — the rheumatologists leading Young Adult Rheumatic Disease (YARD) clinics, or others testing alternative models for the delivery of transition care, as was the case in Chang, *et al*'s analysis. These champions will serve an invaluable role in studying and adapting models of care to reflect best practice to meet the needs of our young adult patients and ensuring a timely transition to YARD clinics, appropriate follow-up care, and stringent adherence to medications. That said, there is unequivocal value in all rheumatologists, on both the pediatric and adult sides, having facility with the tenets of transition, to promote (at least) "essential" best practices if the luxury of referral to such a specialized clinical model does not exist.

There are consistent differences in the resources and infrastructure available on the pediatric and adult sides, with the latter almost universally being more austere[15]. Nursing, social work, and allied health support, not to mention resources such as patient information sessions and development of IT platforms to better support young adult patients, are perceived as advantages in the provision of care for transitioning young adults, but they are resource- and cost-intensive. The ability to better lobby for support for the implementation of any of these professionals and/or services into transition programs would be bolstered by data on their roles in supporting best practices, as outlined in the EULAR/PReS standards and recommendations.

It seems the old pediatric adage that "children are not just small adults" remains of value in our reflection on the provision of care to young adults. There is no better time than the present to work together to improve these patients' futures.

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