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Prolonged lapses between pediatric and adult care are associated with rise in HbA1c and inpatient days among patients with type 1 diabetes

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Abstract

Aim: To quantify the association between the duration of the pediatric-to-adult care transfer with glycemic control among patients with type 1 diabetes (T1D).

Methods: This retrospective cohort study included patients with T1D who completed transfer between pediatric and adult diabetes clinics at a single academic medical center between 2004 and 2020. The primary exposure was time from the last pediatric to first adult diabetes care encounter. The primary outcome was the average HbA1c in the first year after entry into adult care.

Results: A total of 449 patients (mean age at transfer 19.8yrs, 51.7 % male) were included for analysis. Transfer required a median of nearly 5 months (196 days; IQR:93–251) and in adjusted and unadjusted models was strongly associated with increased HbA1c within 1 year of transfer (0.19 %, 2 mmol/mol; 95 %CI:0.04 %–0.33 %) for each 6 months of latency. In secondary analyses, transfer latency also exhibited a significant association with days spent hospitalized (IRR 1.23 per 6 months; 95 %CI:1.08–1.33).

Conclusions: Our findings isolate and quantify the impact of prolonged lapses in care associated with the pediatric-to-adult care transfer. These findings underscore the need for

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.diabres.2022.110113.

providers and healthcare systems to improve this care transition in order to improve outcomes for this vulnerable patient population.

Keywords

Type 1 Diabetes; Transition; Transfer; Young Adult; Care Utilization

1. Introduction

Adolescents and emerging adults with type 1 diabetes are particularly vulnerable to acute and chronic complications associated with this chronic disease. [1,2] Cross-sectional studies have consistently shown that among all age groups, average HbA1c is the highest among late adolescents and early young adults. [3,4] Notably, when compared to the general population, 20–29 year old males with type 1 diabetes face a threefold increase in mortality, while females in this age group have a six-fold increase in mortality. [5] Among many potential personal, social, and health system factors, difficulty in transferring care between pediatric and adult care models has been identified as a modifiable factor contributing to worsening disease control. [1,6,7].

Care transition – the planned purposeful process of moving from a pediatric-to-adult model of care – ideally involves years of planning and ongoing follow-up for patients, providers and their social support systems. [8–11] Transition is highlighted by the transfer between pediatric and adult care, which, for patients with type 1 diabetes, is a high-risk event for loss to follow-up, rising HbA1c, hospitalization, and mortality. [2,12–16] Previous work quantifying this impact has largely relied either on age-based cut-offs (e.g., age 18 years) to define care transfer, included only pediatric or adult patients, or did not define a particular time of transfer due to inherent challenges of tracking longitudinal outcomes between distinct health care systems. [3,11–15,17] Thus, while clinical experience and qualitative data strongly suggest prolonged transfer as a risk factor for worsened outcomes among these patients, quantitative data to isolate its impact on changes in important diabetes-related outcomes are limited. [13,15,18,19].

In this study, we used detailed electronic health record (EHR) data including pediatric and adult clinic, laboratory, and hospital admission data to identify a subset of patients who transferred care within a single academic medical center. This rich dataset allowed us to analyze trends in HbA1c and healthcare utilization with respect to age and relative to key events in the transfer of care. We sought to isolate the association of prolonged transfer from pediatric-to-adult care on both short and long-term measures of disease control as well as changes in healthcare utilization within this cohort.

1.1. Subjects, Materials, and Methods

1.1.1. Pediatric type 1 diabetes clinical environment and cohort identification

—The current study is a retrospective cohort study of patients with type 1 diabetes from a single medical center in the Southeast United States. Pediatric and adult patients received outpatient care within a single outpatient clinic floor in adjacent offices. Pediatric and adult providers also provided outpatient care to a small proportion of patients at outlying satellite

clinics, all of which were included for analysis. The decision for transfer to adult care occurred at the discretion of the pediatric provider with no established or mandated age of transfer to adult care. For the duration of the study period, there were no formal transition preparation or receivership programs implemented within either the pediatric or adult clinics. Eligible patients were identified using an automated search of EHR data including the records from these pediatric and adult diabetes practices. In order to identify patients with established care in the pediatric clinic, patient records were included if they had three consecutive years with at least one clinic visit per year in the pediatric diabetes clinic prior to 3/15/2020. Patients were identified as having type 1 diabetes by an ICD diagnosis code of type 1 diabetes mellitus (ICD10: E10.*) submitted by the billing provider at the time of the visit. Previous work suggests that provider-assigned diagnosis of type 1 diabetes is a highly specific indicator of diabetes diagnosis. [20] Diagnosis was further confirmed by manual chart review of those patients taking non-insulin medications, and those with clinic visits in the pediatric pulmonary clinic to exclude those with type 2 diabetes and cystic fibrosis-related diabetes. After validation, a total of 4,128 patients met our criteria for being engaged in pediatric diabetes care and were eligible for further analysis.

1.1.2. Transfer cohort identification—Pediatric patients engaged in care for type 1 diabetes were included in our transfer cohort if they had undergone a transfer to the adult diabetes clinic – defined as having at least two clinic visits in the adult diabetes clinic prior to 3/15/2020. Furthermore, to identify only those patients who transferred their care directly to our adult diabetes clinic – without significant follow up by an external provider – we included only those patients who completed transfer to the adult clinic within 2 years of their last pediatric clinic visit. Additionally, due to the small number of patients with only primary care follow up for their diabetes care in our center (n = 2), these patients were excluded from our analysis. Among the 4,128 patients identified as being followed in our pediatric clinic within this timeframe, 449 met our definition of an observed, internal care transfer and were included in our primary analysis.

1.1.3. Visit identification and lab data extraction—We analyzed lab values and health system encounters by study subjects to the pediatric diabetes clinic, emergency department and pediatric inpatient units as well as any adult outpatient, inpatient or emergency department visits within the medical center's facilities during the study period. Data prior to 1/1/2004 are not complete in the EHR and were excluded. Furthermore, visits completed after 3/15/2020 were also excluded due to disruptions in clinical care associated with the COVID-19 pandemic and documented elsewhere. [21].

1.1.4. Transfer date determination and transfer 'Epoch' designation—Using visit dates to the pediatric and adult diabetes clinics, a timeline of care was determined for each patient (Fig. 1). The first visit date to the pediatric diabetes clinic was assigned as the date of diagnosis, and the date of the last pediatric diabetes clinic visit was used as the end date for pediatric diabetes care. Thus, any clinical encounter within this interval was coded as occurring in the *pediatric care epoch*. Similarly, visits falling between the first adult diabetes clinic visit to the end of the study period were identified as occurring in the *adult care epoch*. Finally, visits falling after the last pediatric and before the first adult visits

were coded as being in the *transition epoch* regardless of the care site (adult or pediatric associated) where the visit occurred. All subsequent analyses used these care epochs to determine if an encounter or laboratory value was pediatric, transition or adult.

1.1.5. Exposure—The primary exposure for the study was transfer latency, defined as the time (in days) from the last pediatric to the first adult diabetes visit. Subsequent analysis scaled transfer latency by six months (180 days) for ease of interpretation on a clinically relevant time scale. [22].

1.1.6. Outcomes—The primary outcome was the mean HbA1c measured at all visits in the first year of the adult care epoch with pre-planned sensitivity analysis to evaluate HbA1c time-horizons at 2 years and all visits. *A priori* secondary outcomes were ED visits and days admitted in the first year after transition. These visits were determined by simple counts of patients encounters meeting these criteria during the transition epoch for each patient standardized to the duration of the transition epoch for these patients.

1.1.7. Ethics statement—This project was determined to be exempt research by the Vanderbilt Institutional Review Board [VUMC IRB# 182241]. In accordance with the ethical framework previously described for Research Derivative studies, [23] all investigators must have IRB determination prior to accessing the resource, and also signed a standard data use agreement.

1.1.8. Statistical Methods—Transfer latency was summarized by demographic and clinical characteristics using standard descriptive statistics. HbA1c was summarized by age and by time since last pediatric visit using smoothing splines. Multivariable regression models with different levels of adjustment quantified associations between transfer latency (per 6-month increase) and outcomes: linear regression for HbA1c, which exhibited a symmetric distribution, and Poisson regression for annualized ED visit and days admitted. Adjustment covariates included demographic characteristics and care-related factors. Demographic characteristics included gender, race/ethnicity as recorded in the EHR (non-Hispanic White, non-Hispanic Black, Hispanic), insurance type (public, private), and age at diagnosis, and care-related factors were HbA1c in the year prior to transition, pediatric visit frequency, and occurrence of the last pediatric visit before or after 1/1/2010 (to account for temporal trends arising from implementation of the Affordable Care Act). For ED visit and hospitalization outcomes, the number of these visits in the year prior to transfer was also included in adjusted models. In sensitivity analyses, models were rerun with increasing HbA1c time-horizons – 2 years after transfer completion and all visits after transfer as well as by requiring 1 or 2 years to pediatric and adult follow up. All analyses were completed using Stata v16.1 (StataCorp, College Station, Texas). We followed standardized guidance for reporting observational studies. [24].

1.2. Results:

1.2.1. Cohort Demographics—Among 4,128 patients followed in our pediatric diabetes clinic, we identified 449 patients who met inclusion criteria for our transfer cohort with an observed transfer of care to our adult diabetes clinic between 1/1/2004 and

3/15/2020. Demographics of the total pediatric clinic cohort as well as the transfer cohort are presented in Table 1. Overall, the cohort that completed transfer to an adult provider within two years of their last pediatric visit was more likely to be non-Hispanic White (86.7 % vs 80.7 %), have a similar HbA1c in the last year prior to transfer to adult care (8.8 % vs 8.9 %) and have a later age at diagnosis (11.5yrs. vs 9.5yrs) as compared to the population of pediatric clinic patients who did not meet our inclusion criteria for the transfer cohort. We also noted a striking difference in insurance providers, with only 8.0 % of those completing transition within our clinic having Medicaid as their primary insurance, whereas Medicaid covered nearly 30 % of patients in the total pediatric population.

1.2.2. Trends in HbA1c and transition timing—As with previous cross-sectional and longitudinal studies, our cohort exhibited a gradual rise in mean HbA1c beginning in late adolescence with a peak at age 18 years 6 months and a subsequent decline in mean HbA1c across the early to mid 20 s (Supplementary Figure S1). [3] Within our cohort, the mean age patients completed their last pediatric clinic visit was 19.3 years (SD 1.3) while the mean age at the first adult clinic visit was 19.8 years (SD 1.3). Overall, the mean HbA1c within the first year before transfer and the first year after transfer, were nearly equal: 9.0 % (75 mmol/mol; SD 1.9 %) and 8.9 % (74 mmol/mol; SD 2.0 %), respectively.

1.2.3. Association between transfer latency and HbA1c after transfer to adult care—Median transfer latency – the time from the last pediatric diabetes visit to the first adult diabetes visit – was approximately 5 months (144 days; IQR 93 – 251). Notably, 38.9 % (175) of patients had latencies of more than 6 months and 13.5 % (61) were observed to have more than a year between their last pediatric and first adult visits. Transfer latency was observed to substantially differ across levels of multiple social and clinical factors, including race/ethnicity, insurance status, age of diagnosis, pediatric HbA1c, and frequency of both admissions and clinic visits while in pediatric care (Table 2). In particular, median transfer latency was greater among non-Hispanic Black patients compared to non-Hispanic White and Hispanic patients, and among patients insured by Medicaid compared to those with private insurance.

In our primary analyses, we observed an increase in average HbA1c of 0.31 % (3 mmol/mol; 95 %CI 0.09 %–0.53 %) for every 6 months of delay between the last pediatric and first adult visits (Table 3). This difference was attenuated but remained statistically significant after covariate adjustment: 0.19 % (2 mmol/mol; 95 %CI 0.04 % – 0.33 %). These findings were robust in pre-specified sensitivity analyses extending HbA1c values to include those 2 years after transfer as well as including all adult HbA1c values (Supplementary Table S1). Fig. 2 shows trends in HbA1c relative to the last pediatric clinic visit. Those with the shortest transfer latency (<3 months) saw a modest decrease in mean HbA1c from their last pediatric to first adult clinic visits (9.1 % vs 8.8 %) while those that took more than 6 months between pediatric and adult visits saw a rise in HbA1c across this period (9.2 % vs 9.5 %). Those completing transfer between 3 and 6 months had no significant change in their HbA1c during their latent period (8.7 % vs 8.7 %). Notably, while those with transfer latencies shorter than 6 months saw overall trends toward lower HbA1cs over the first 36 months after transfer to adult care, those who took more than 6 months to transfer saw no

such decline in HbA1c over this period with HbA1c remaining roughly unchanged over this period.

1.2.4. Association between transfer latency and care utilization—In addition to the association between latency and HbA1c observed in our primary analysis, unadjusted and adjusted analyses of measures of care utilization – ED visits and admission days within 1 year of the last pediatric visit – showed statistically significant and clinically meaningful increases in hospitalization days with prolonged transfer latency. We observed a 23 % increase in inpatient days for every 6 months of transfer latency (Incidence Rate Ratio, IRR 1.23; 95 %CI 1.11–1.38) after covariate adjustment. In our unadjusted analysis, we observed a statistically significant 25 % increase in ED visits for every 6 months of transfer latency (IRR 1.25 (95 %CI 1.04–1.51), an association which reduced in magnitude and below the threshold for statistical significance in adjusted analyses (IRR 1.09 (95 %CI 0.90–1.44)).

2. Discussion

This retrospective cohort study used a novel study design to isolate the impact of pediatric-to-adult care transition on disease control among patients with type 1 diabetes. Our innovative approach – analyzing data based on time rather than age relative to important events in the transfer of care from pediatric-to-adult providers–provides unique insight into trends in HbA1c across these milestone events in care. We were able to quantify the impact of prolonged transfer latency on markers of disease control and care utilization. We observed a clinically and statistically significant association of transfer latency with both glycemia and inpatient hospital days. While not statistically significant, we also observed clinically significant increases in ED utilization with prolonged transfer, which was likely due to the relatively low frequency of these events, limiting our power to detect statistically significant differences.

It is important to note, as highlighted in Table 1, that the cohort included in our primary analysis is not representative of the underlying population of patients with type 1 diabetes in our clinic or according to population studies. Patients in our transfer cohort were significantly more likely to be non-Hispanic White, have private insurance, and lower average HbA1c levels in the pediatric period than those in the general population of pediatric type 1 diabetes. While these differences limit the generalizability of our estimate of the effect of latency on HbA1c, the persistence of this association, even in a cohort of young adults likely to have greater resources than the overall clinic population, strongly suggests that our findings underestimate the negative impact transfer latency has on disease control and care utilization among all patients with type 1 diabetes.

Among those patients with public insurance and from underrepresented groups who were included in our cohort had marked increases in transfer latency. Therefore, our data suggest that the pediatric-to-adult transfer appears to exacerbate existing health disparities within our system both in fewer patients completing this transfer, and with poorer outcomes among those who do successfully transfer. While this dataset provides little additional context for these findings, the concordance of our observations with other recent studies adds further support to these conclusions and suggest that social determinants of health

such as access to time off for medical care and transportation may play a role in these findings. [15,25] The disparate outcomes based on income and race in this study merit further investigation both to confirm and explore these findings as well as to assess the impact of potential interventions to address these issues such as increased use of telehealth or more comprehensive approaches to care which address the additional barriers faced by these groups.

This study has implications for multiple stakeholders within health care systems. First, for pediatric providers, our findings emphasize the importance of transition planning to ensuring close follow up with an adult provider after transfer from pediatric-to-adult care. Recent work has shown improved outcomes for pediatric-based transition programs using care navigators to assist patients in establishing care with adult providers. [1] The current study provides data to quantify this impact and provides further insight into one potential mechanism for these gains. Second, for adult providers, these findings emphasize the importance of developing systems to accept pediatric patients into adult practice. Maintaining and reinforcing positive health behaviors is a key goal of frequent clinic visits which is demonstrated in our data and will help to avoid short- and long-term diabetes-related complications. Third, ensuring a smooth transfer of care also may have significant benefits to hospitals and payors as demonstrated by the association between increased transfer latency and high-cost care utilization such as hospitalizations and ED visits.

The current study has several strengths: to our knowledge, it is the largest US cohort with complete longitudinal data across the pediatric-to-adult transition among patients with T1D for which the exact timing of the pediatric-to-adult care transfer is known. [26] The rich clinical and laboratory data in our dataset allowed us to demonstrate the heterogeneity of transfer initiation and duration across this population and how this correlated with important clinical outcomes. Compared to other similar studies, our ability to isolate the exact timing of transition independent of age provides the opportunity to better understand the effect of this event independent of co-occurring biological and social changes within this age group [4,12,27].

Among the limitations to our data are concerns about generalizability and completeness of our dataset. Given the fragmented nature of medical record data systems, follow up information including the granular visit-level data needed to conduct these analyses were not available for all patients in our pediatric clinic, as noted above. Thus, even within this narrow cohort, our estimates of the association of transfer latency with ED utilization and hospitalized days are likely underestimates of overall utilization by these patients.

Overall, our findings support that prolonged time between the last pediatric visit and first adult visit in patients with T1D is a significant risk factor for worsened disease control and healthcare utilization – as measured by HbA1c and hospital days – after transfer to adult care. This emphasizes the importance of optimizing care at this care transition on disease control. Future work is needed to replicate these results in diverse populations within the US healthcare context and to quantify the impact of prolonged transfer latency on rates of future complications.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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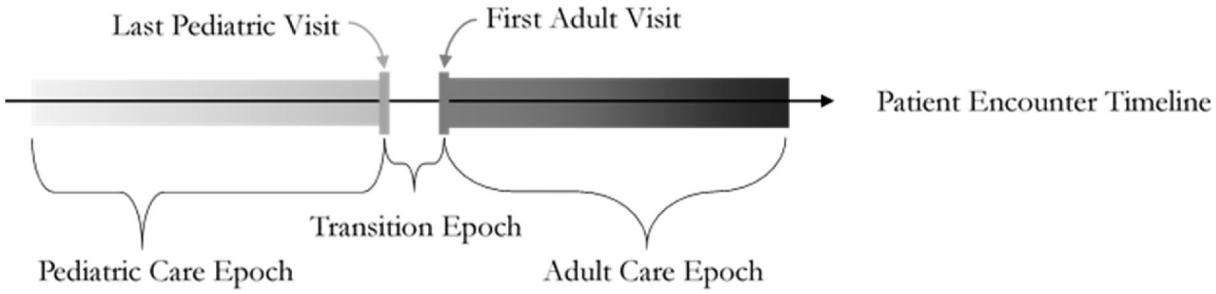
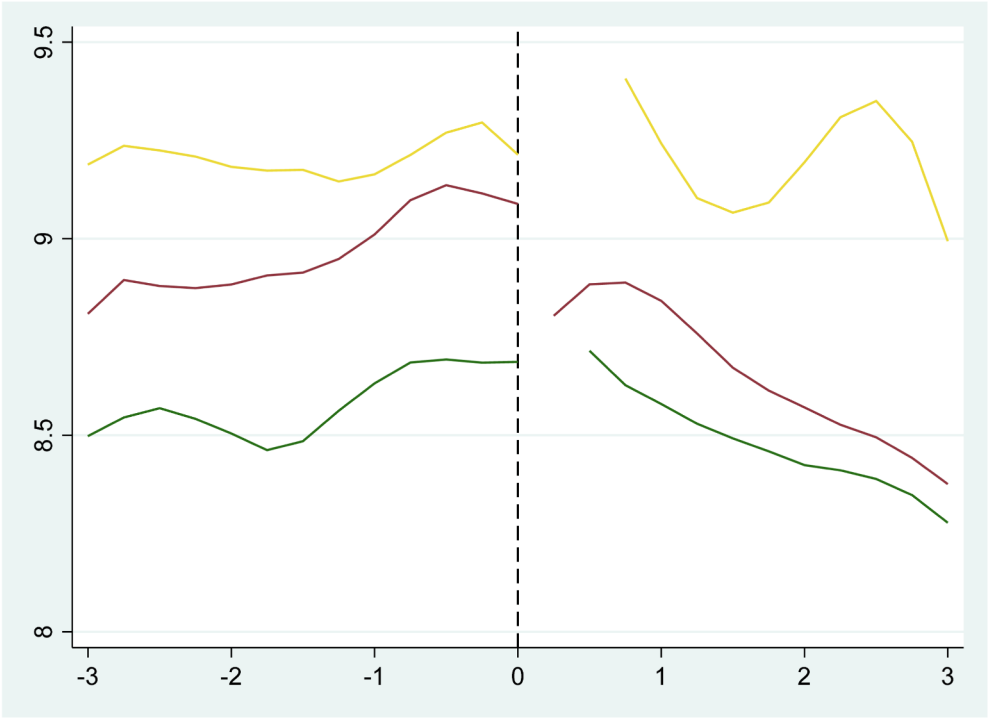


Fig. 1.

Diagram of Analytic Approach to Each Patient's Care Encounter Timeline. Above diagram represents the analytic approach taken for visits for each patient. Visits and laboratory values that occurred/were obtained before the last pediatric diabetes clinic visit were analyzed as pediatric while those occurring after the first adult visit were similarly deemed to be belonging to the adult care epoch.



Transfer Latency[a]	Number of Patients Contributing Data at each year interval						
<3 months	59	63	61	85	52	34	37
3-6 months	118	141	144	185	112	91	81
>6 months	97	115	119	168	73	70	61

Fig. 2.

HbA1c (%) Relative to Time of Last Pediatric Clinic Visit Across Transfer Latency Cohorts

[a] Transfer Latency strata chosen based on standard care recommendations for clinical monitoring for patients with type 1 diabetes. [22].

Table 1

Demographic and Clinical Characteristics of Transfer and Non-Transfer Pediatric Patients.

Characteristic	Transfer Patients	Non-Transfer Patients
Total Number	449	3,679
Male Gender (%)	232 (51.7 %)	1940 (52.7 %)
Race/Ethnicity		
Non-Hispanic, White (%)	390 (86.7 %)	2968 (80.7 %)
Non-Hispanic, Black (%)	36 (8.0 %)	360 (9.8 %)
Hispanic (%)	10 (2.2 %)	106 (2.9 %)
Medicaid insurance at last pediatric visit (%)	36 (8.0 %)	1088 (29.6 %)
Age (in years) at Diagnosis (Mean, SD)	11.5 (3.5)	9.5 (4.1)
Mean A1c while in pediatric care (SD)	8.8 % (1.4)	8.9 % (1.5)
Mean A1c while in the last year of pediatric care (SD)	9.0 % (2.0)	N/A
Average pediatric visits per year (SD)	3.6 (1.9)	4.1 (1.8)
Average pediatric hospital inpatient days per year (SD)	0.15 (0.37)	0.24 (0.59)
Median duration (in months) of pediatric follow up (IQR)	95.7 (60.5 – 129.1)	N/A
Median duration (in months) of adult follow up (IQR)	46.2 (19.4 – 75.6)	N/A

All patients were seen in 3 consecutive years in the pediatric diabetes clinic with a primary diagnosis at each of these visits of Type 1 Diabetes. Patients included in the transfer cohort completed at least two clinic visits in the adult diabetes clinic at the same medical center.

Table 2

Transfer Latency by Demographic and Clinical Characteristics.

	Days of Transfer "Latency" (Median, IQR)
All Patients	146 (94 – 265)
Gender	
Female	145 (93 – 257)
Male	143.5 (92.5 – 248.5)
Race/Ethnicity	
Non-Hispanic White	142 (93 – 249)
Non-Hispanic Black	194 (96 – 312)
Hispanic	129.5 (70 – 177)
Last pediatric insurance coverage	
Private Insurance	138 (92 – 237)
Medicaid	244.5 (144 – 391)
Age at Diagnosis	
< 8 years	177 (96 – 326)
8 – 14 years	146.5 (95 – 252)
>=14 years	119.5 (91 – 213)
Average HbA1c 1 year prior to transition to adult care	
< 7 %(<53 mmol/mol)	112.5 (92.5 – 233)
7 – 8.5 % (53–69 mmol/mol)	145 (93 – 232)
8.5 – 10 % (69–86 mmol/mol)	158 (96 – 257)
>= 10 % (greater than86 mmol/mol)	146 (91 – 264)
Average visits to the pediatric clinic per year	
< 2	181.5 (99 – 348)
2–4	156 (95 – 257)
>= 4	116.5 (89 – 182.5)
Ever Admitted for T1D?	
No	145 (95 – 252)
Yes	138.5 (90.5 – 248.5)
Last Peds year	
Before 2010	146 (93 – 300)
2010 or later	142.5 (92.5 – 236)

Table 3

Regression Models for Transfer Latency association with Primary and Secondary Outcomes.

	Difference in HbAlc (%) in the first year in adult care[a]	p value	IRR for ED visits in the first year in adult care[a]	p value	IRR for inpatient days in the first year in adult care[a]	p value
Model 1 (Unadjusted)	0.31 (0.09 to 0.53)	0.005	1.25 (1.04 to 1.51)	0.018	1.41 (1.27 to 1.58)	<0.001
Model 2 (Demographic Adjusted)[b]	0.28 (0.06 to 0.50)	0.014	1.04 (0.86 to 1.27)	0.67	1.21 (1.03 to 1.28)	0.001
Model 3 (Fully Adjusted)[c]	0.19 (0.04 to 0.33)	0.011	1.09 (0.90 to 1.44)	0.39	1.23 (1.11 to 1.38)	<0.001

[a]Contrasts (i.e., mean difference in HbA1c, incidence rate ratios) are for every additional 6 months of transfer latency.

[b]Demographic factors: gender, race, insurance type (public vs private) and age at diagnosis.

[c]Fully adjusted model factors: demographic factors and A1c in the year prior to transition, pediatric visit frequency, last pediatric visit before or after 2010. For ED visit and hospitalization outcomes the number of these visits in the year prior to transfer was also included in the fully adjusted model.