

Identifying Disparities in Pediatric Specialty Referral
Completion

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Abstract

Identifying Disparities in Pediatric Referral Completion

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Background: Disparities exist in access to pediatric specialty care. The extent to which the referral and scheduling processes contribute is not well understood.

Objective: To determine whether sociodemographic factors are associated with appointment scheduling and completion in a cohort of pediatric specialty referrals.

Methods: This was a retrospective cohort study of children referred for specialty care to a large children's hospital between 03/01/19 – 03/31/21. Referrals for children who were receiving primary care at clinics within 5 miles of the hospital were included to create a local cohort of children. Generalized estimating equations tested for associations between demographic variables (race and ethnicity, language, and insurance type serving as proxies for structural racism and discrimination) and odds of scheduling and completing a referral, while adjusting for clustering of multiple referrals per child. Cox proportional

hazard models assessed time to appointment scheduling and completion. Multivariable analyses controlled for child age, specialty volume, and type of visit.

Results: Of the 38,334 new referrals, 62% resulted in appointment scheduling and 54% resulted in completion. For children with Black race, Native Hawaiian/Pacific Islander race, Spanish language preference, and public insurance, < 50% of referrals resulted in a completed appointment. In adjusted analyses, Asian, Black and publicly insured children had significantly lower odds of both scheduling and completing referrals, with adjusted odds ratios ranging from 0.70 to 0.94. The adjusted hazard analysis indicated that families with non-English language preference, publicly insured children, Black children, and Hispanic children experienced longer times to scheduling and completing appointments.

Conclusion: Significant disparities exist in the odds and timing of referral scheduling and completion by race and ethnicity, language, and insurance type for a cohort of children local to the specialty care center. This variation indicates that institutional scheduling procedures structurally disadvantage some families more than others. Comprehensive metrics for specialty care access are necessary as current measures maybe overlooking disparities that could be addressed by restructuring scheduling and referral processes. Tracking access metrics and family experience of care can help guide interventions to simplify and enhance the inclusiveness of the referral process, which may help to reduce disparities in accessing pediatric specialty care.

Introduction

Nearly 20% of children in the United States have a special health care need, a majority of whom require specialized services.¹ Yet, nearly 1 in 3 referrals to pediatric specialists does not result in an attended appointment.² Racial and ethnic, socioeconomic, and geographic disparities exist in access to pediatric specialty care.^{ii,3,4} The extent to which referral and scheduling processes contribute to disparities in accessing specialists is not well understood.

Referral process breakdowns, resulting in lack of follow-up after referral transmission, have been documented as potential causes of missed or delayed diagnosis for several conditions.^{5,6,7,8} The Institute for Healthcare Improvement identifies referral process breakdowns as a major issue of patient safety.⁹ Multiple studies have also identified that diagnoses necessitating specialty evaluation are often disproportionately delayed for racial and ethnic minorities and publicly insured children.^{10,11} Understanding the drivers of referral breakdown appears to be essential for patient safety and equitable healthcare access. In this study, we examined variation in referral completion by sociodemographic factors. Our study builds on previous studies by removing confounding related to distance from referral center.^{ii, iii} Additionally, unlike previous studies, we assessed whether the length of time to obtain specialty care varies by sociodemographic factors. Sociodemographic factors served as proxies for structural racism and discrimination to shed light on how institutional practices and procedures for referral scheduling impact specialty access for different patient groups.

Our study questions were as follows: (1) What are the overall proportions of new referrals that are scheduled and completed? (2) Which child sociodemographic characteristics are associated with lower likelihood of scheduling and completing an appointment? (3) What is the average time to scheduling and completing a new referral? We hypothesized that a large proportion of

new referrals would not be scheduled and that despite geographic proximity to the referral center, the likelihood of scheduling and completing a new referral as well as time to scheduling and completing a referral would vary by child sociodemographic factors.

Methods

We conducted a retrospective cohort study of children for whom a referral for specialty care was received and recorded in the electronic medical record of a large, tertiary care children's hospital between 03/01/19 to 03/31/21. To create a cohort of children with geographic proximity to the hospital, we only included referrals for children who were receiving primary care at clinics within 5-miles of the hospital. Beyond this radius, reaching the hospital sometimes requires travel by ferry, posing a potential geographic access barrier. Restricting to this region also served to identify a group of children with limited amount of data missingness. The 5-mile radial region surrounding the hospital is primarily urban or suburban. Several primary care clinics in this region provide care to children with diversity in income, race and ethnicity, and language.¹² Children up to 18 years of age were deemed eligible if they had a new referral during the study period. A new referral was defined as a referral to a specialty clinic in which the child had not been seen for an appointment in the previous 3 years. If a child had a referral to more than one specialty, each referral counted as a unique referral. If a child had more than one referral to a given specialty, the earliest referral date was used for analysis. We included referrals to 34 medical and surgical subspecialties and appointments with physicians and mid-level practitioners (i.e., nurse practitioners, physician assistants. Appointments at the main hospital campus and satellite clinics were included.

We excluded appointments with allied health providers (i.e., nutrition, social work, etc.) and appointments for procedures not accompanied by a provider visit. We excluded referrals to 3

subspecialties due to very low volume totaling < 1% of all referrals throughout the study period. Appointment data was obtained for a minimum of 6 months after the date the referral was recorded. Referrals scheduled for an appointment > 6 months after the referral was recorded were excluded from the analysis (N = 452) as were children scheduled for an appointment taking place after the last date of follow up in September 2021 (N = 21). All data were extracted from administrative medical records of the hospital.

Outcomes

We examined 4 primary outcomes of interest: odds of scheduled referral, odds of completed referral, time to scheduling, and time to completed referral. We defined a scheduled referral as a referral that resulted in a scheduled appointment. A completed referral was one that resulted in an attended appointment. Time to scheduling was calculated as number of days between the date of referral receipt and the date of scheduling. Time to completed referral was calculated as the number of days between the date of referral receipt and date of the attended appointment.

Independent Variables

We evaluated sociodemographic factors of child race and ethnicity, language preference, and insurance type, as independent variables of interest. Race and ethnicity and language preference data were self-reported by children or their families. In some cases, sociodemographic data in the records were derived from information provided by the child's primary care clinic and may not have been verified with the child's family. Race and ethnicity were categorized into mutually exclusive categories: American Indian/Alaska Native, Asian, non-Hispanic Black (hereafter referred to as "Black"), Hispanic, Native Hawaiian/Pacific Islander, Multiracial/Other, non-Hispanic White (hereafter referred to as "White"), Refused (children/families who declined to respond), or Unknown. Language was classified according to child's listed preference for

medical communication in the electronic medical record and grouped into English or Other.

Insurance type was categorized as either Commercial (including both fee for service and managed care) or Public/Other (Medicaid, Medicare, Tricare, etc). This study was approved by the Seattle Children's Hospital Institutional Review Board.

Statistical Analysis

Results were summarized descriptively by referral scheduling status and appointment completion status using counts and percentages for categorical variables and means with standard deviations or medians with interquartile ranges for continuous variables. Continuous variables were assessed for normality using Q-Q plots and histograms.

Generalized estimating equations (GEE) methods, accounting for clustering of repeated observations (e.g., multiple referrals) across children were used to assess univariable and multivariable models and to compute odds ratios of scheduling and completing a new referral. Cox proportional hazard models using the robust sandwich estimate of the covariance matrix were used to assess hazard ratios for hazard rate of scheduling an appointment (among those with scheduled appointments) and hazard rate of completing an appointment (among those with completed appointments). For race and ethnicity, children were compared to a weighted grand mean (estimate) rather than a single comparison group to avoid centering on one group.¹³

Children with missing data were excluded from multivariable models, however those who declined to report race and ethnicity were included as their own group to assess whether these children may have unique referral patterns.

Models were adjusted for the child's age and specialty volume for all outcomes. Specialty volume was divided into terciles (low, medium, high) based on median appointment requests per day over a 90-day period for each specialty as of September 2021. Hazard models assessing time

to scheduling and completing an appointment were also adjusted for appointment type (in-person or virtual). All analyses were completed using SAS 9.4 (Cary, NC).

Results

Referral and Participant Characteristics

Overall, of the 38,334 new referrals, 62.1% resulted in a scheduled appointment and 54.1% resulted in an attended appointment in the unadjusted analysis [Table 1]. For children with Black race, Native Hawaiian/Pacific Islander race, Spanish language preference, and public insurance, < 50% of referrals resulted in a completed appointment. Among referrals that were scheduled, the median time to scheduling an appointment was 2 days. Among referrals that resulted in appointment attendance, the median time to completing an appointment was 21 days. Compared to the overall group median of 2 days, families with non-English language preference had notably longer times to appointment scheduling; those with Spanish language preference had a median scheduling time of 16 days and those with other language preference had a median scheduling time of 10 days. Race and ethnicity, language preference, and insurance data were missing for < 2.5% of all referrals.

Univariable & Multivariable Analyses

Odds of scheduling and completing referral

The unadjusted odds of scheduling and completing a new referral were lower for Black children, publicly insured children, and children from families with a non-English language preference. Hispanic children also had lower unadjusted odds of scheduling a new referral.

The adjusted odds of scheduling and completing a new referral were lower for Asian children, Black children, and publicly insured children. Adjusted odds of scheduling were 6% lower for Asian children (0.94, 95% CI: 0.89, 0.99), 15% lower for Black children (0.85, 95% CI: 0.77,

0.93), and 30% lower for publicly insured children (0.70, 95% CI: 0.66, 0.75). Adjusted odds of attending a new referral appointment were 8% lower for Asian children (0.92, 95% CI: 0.88, 0.97), 22% lower for Black children (0.78, 95% CI: 0.71, 0.85), and 30% lower for publicly insured children (0.70, 95% CI: 0.66, 0.74).

Time to scheduling and completing referral

In the unadjusted analysis, Black children, Hispanic children, publicly insured children, and children from families with non-English language preference, had a lower hazard of scheduling, suggesting longer time to appointment scheduling. Additionally, among those with completed appointments, Black children, Hispanic children, Native Hawaiian/Pacific Islander children, publicly insured children, and children from families with a non-English language preference had a lower unadjusted hazard of appointment completion, suggesting longer times to appointment completion.

The adjusted hazard analysis indicated that time to scheduling was 3% longer for Black children (aHR 0.97, 95% CI: 0.94, 0.99), 5% longer for Hispanic children (aHR 0.95, 95% CI: 0.94, 0.97), 12% longer for publicly insured children (aHR 0.88, 95% CI: 0.87, 0.89), and 32% longer for families with non-English language preference (aHR 0.68, 95% CI 0.67, 0.69). Among completed appointments, time to completed appointment was 3% longer for Hispanic children (aHR 0.97, 95% CI: 0.95, 0.98), 7% longer for families with non-English language preference (aHR 0.93, 95% CI: 0.91, 0.96), and 12% longer for publicly insured children (aHR 0.88, 95% CI: 0.86, 0.89).

Discussion

Among new specialty referrals, almost one-half of referrals did not result in an attended appointment. In the multivariable analysis, we found that Asian, Black, and publicly insured

children had lower odds of completing a new referral appointment. Similar to previous studies, language preference was not associated with likelihood of referral completion in the multivariable analysis. However, the hazard analysis indicated that children from families with non-English language preference and publicly insured children experienced significantly longer times for both scheduling and completing a new referral appointment.

The overall referral completion rate and the multivariable findings of this local cohort were similar to other studies on referral completion that were done over larger geographic catchment areas.ⁱⁱⁱ By focusing on a local cohort, the results from this study demonstrate that geographic proximity to a large specialty care center does not attenuate sociodemographic disparities in referral completion. The outcomes evaluated in this study also identified some actionable bottlenecks in the referral process that vary by family sociodemographic characteristics. Notably, there was a large drop off between the number of received referrals and number of scheduled referrals, with only two-thirds of referred children being scheduled for an appointment. This bottleneck disproportionately impacted Asian, Black and publicly insured children. For families with non-English language preference, the setback was not in completing a new referral, but rather in the time it took to complete a new referral. Publicly insured children were impacted by both bottlenecks: lower odds to scheduling an appointment and longer times to completing an appointment. To our knowledge, this is the first study of pediatric specialty care referrals that describes scheduling and completion rates for American Indian/Alaska Native and Native Hawaiian/Pacific Islander children. We did not have enough data to reach significance in the multivariable analysis for these groups. Due to their smaller sample size, these children are often left out of analyses or analyses are underpowered to detect significant findings. To make meaningful interpretations and avoid persistent erasure of these groups' experiences, it is

important to consider creation of multi-institutional datasets nationally and advocate for qualitative investigations locally.

The racial, ethnic, language and insurance disparities identified in this study suggest that institutional scheduling procedures structurally disadvantage some families more than others.

These findings raise some important questions about the inclusivity of the scheduling and referral process. Which steps in the referral process cause confusion for families? What difficulties are families experiencing in reaching and communicating with scheduling staff? How well-aligned are available appointment and families' schedules? How is family lack of trust due to systemic racism in healthcare impacting appointment scheduling and attendance?

While there is no nationally recognized standard for ambulatory access metrics for multi-specialty care organizations, current ways of measuring ambulatory access maybe overlooking disparities.¹⁴ At many organizations, ambulatory access is measured by no-show or cancellation rates, which offer limited insight into patient outcomes or experience of care.^{xiv} Some organizations employ more creative approaches for measuring access, but generally these measures are motivated by revenue generating priorities.^{xiv} While this is important for financial sustainability, it is also necessary to track ambulatory access metrics that center equity and patient experience of care.

More comprehensive metrics require consideration of the multiple dimensions of access including affordability (cost of care relative to ability to pay), availability (adequate personnel and resources for care), accessibility (geographic accessibility), accommodation (convenience of care such as hours of operation, telephone access, and language access), and acceptability (patient/family comfort with personnel), as conceptualized by Penchansky and Thomas.^{15,16}

Commonly used ambulatory care metrics, such as no-shows and cancellations, partly reflect the

accessibility and affordability dimensions of access. But as suggested by the results of this and other studies, different dimensions of access maybe more or less relevant for different sociodemographic groups. For groups experiencing structural racism, the acceptability of offered care may be more relevant than accessibility. The accommodation dimension may have more relevance for families with non-English language preference, where timeliness of services impacts access more than cancellation rates. Metrics tracking disparities in scheduling can shed light on how accommodating current scheduling processes are for those that have the most difficulty making the first appointment. By more comprehensively measuring different dimensions of access, healthcare organizations can begin to center equity in pediatric ambulatory specialty care access.

Finally, tracking metrics for access is necessary but not sufficient. Metrics help identify disparities in late presentation to care and decreased care seeking but do not clarify the upstream financial, structural, and cognitive barriers faced by families when accessing specialty care.¹⁷ Metrics need to be supplemented by routinely tracking family experience with access to care. The Agency for Healthcare Research and Quality's (AHRQ) CG-CAHPS (Clinician and Group Survey) offers instruments to measure patient experience more comprehensively and inform organizational improvements.

This study has several limitations. It is a single institution study, so generalizability maybe limited. However, given that the study replicates findings from other single-site studies, these results are likely generalizable to many other pediatric specialty care organizations. Additionally, given the retrospective cohort design, we can measure associations but cannot make causal inferences as to the reasons for the observed disparities. We were limited to data available in the medical record and therefore did not have information about the frequency and quality of

scheduling communication with families nor information on whether insurance authorizations affected referral scheduling and completion, both of which may have resulted in unmeasured confounding. We also did not have information on referrals that were not successfully transmitted to the specialty care center which may have resulted in selection bias.

Despite these limitations, the results of this study suggest some specific and actionable changes to improve access to pediatric specialty care. By tracking a comprehensive set of access metrics and family experience, and actively soliciting family participation in designing referral workflows, specialty care organizations can begin to address barriers faced by families and offer more equitable access to pediatric specialty care.

Tables

Table 1. Referral and sociodemographic characteristics of participants

	Total Number of New Referrals	New Referrals Scheduled	New Referrals with Completed Appointments	Time to Scheduling of Appointment¹ (days) Median [IQR]	Time to Completion of Appointment² (days) Median [IQR]
Overall	38,334	62.1%	54.1%	2 [0-13]	21 [6-60]
Race and Ethnicity					
American Indian/Alaska Native	112	57.1%	52.7%	2 (0 – 10)	15 (7 – 40)
Asian	5,898	63.2%	54.6%	1 (0 – 10)	19 (6 – 57)
Black	2,299	55.3%	44.9%	5 (0 – 21)	28 (8 – 72)
Hispanic	3,571	60.9%	53.2%	5 (0 – 21)	26 (7 – 70)
Multiracial/Other	4,349	62.1%	53.7%	2 (0 – 12)	20 (6 – 55)
Native Hawaiian/Pacific Islander	149	57.7%	48.3%	4 (0 – 18)	24 (8 – 76)
White	18,664	63.8%	56.4%	2 (0 – 13)	21 (6 – 59)
Refused	2,834	63.7%	54.8%	2 (0 – 12)	21 (5 – 58)
Unknown	458	16.6%	12.4%	2 (2 – 14)	20 (5 – 76)
Language					
English	36,497	62.4%	54.4%	2 (0 – 12)	21 (6 – 59)
Spanish	722	55.8%	48.9%	16 (3 – 62)	33 (9 – 86)
Other	1,045	58.8%	50.6%	10 (2 – 37)	27 (8 – 70)
Unknown	70	0.0%	0.0%	-	-
Insurance					
Commercial	29,774	65.0%	57.2%	2 (0 – 11)	20 (6 – 56)
Public or Other	7,695	55.8%	47.1%	6 (0 – 23)	29 (8 – 75)
Unknown	865	19.1%	9.4%	3 (0 – 18)	21 (5 – 64)
Age (in years)*	8.4 (5.5)	5.5	8.1 (5.4)	-	-

* Mean(SD)

¹Among referrals that are scheduled

²Among referrals that result in appointment attendance

Table 2. Odds of referral resulting in scheduled appointment and completed (attended) appointment among children of local primary care clinics referred to a specialty care hospital

	Scheduled Appointment		Completed Appointment	
	Unadjusted OR (95%CI)	Adjusted OR (95%CI)*	Unadjusted OR (95%CI)	Adjusted OR (95%CI)*
Race and Ethnicity†				
American Indian/Alaska Native	0.81 (0.51, 1.27)	0.83 (0.54, 1.29)	0.93 (0.61, 1.43)	0.97 (0.64, 1.46)
Asian	1.02 (0.97, 1.07)	0.94 (0.89, 0.99)	1.00 (0.95, 1.04)	0.92 (0.88, 0.97)
Black	0.73 (0.67, 0.79)	0.85 (0.77, 0.93)	0.67 (0.61, 0.73)	0.78 (0.71, 0.85)
Hispanic	0.92 (0.86, 0.98)	1.01 (0.94, 1.08)	0.94 (0.88, 1.00)	1.02 (0.96, 1.10)
Multiracial/Other	0.97 (0.91, 1.03)	0.96 (0.90, 1.02)	0.96 (0.90, 1.01)	0.95 (0.89, 1.00)
Native Hawaiian/Pacific Islander	0.81 (0.58, 1.13)	0.82 (0.60, 1.14)	0.76 (0.54, 1.08)	0.78 (0.56, 1.10)
White	1.05 (1.03, 1.08)	1.04 (1.02, 1.07)	1.08 (1.05, 1.10)	1.07 (1.04, 1.09)
Refused	1.06 (0.99, 1.15)	1.08 (1.00, 1.16)	1.02 (0.94, 1.10)	1.03 (0.95, 1.11)
Primary Language				
English	ref	ref	ref	ref
Other	0.80 (0.72, 0.88)	0.97 (0.87, 1.09)	0.81 (0.73, 0.89)	1.01 (0.91, 1.12)
Insurance				
Commercial	ref	ref	ref	ref
Public/Other	0.68 (0.64, 0.72)	0.70 (0.66, 0.75)	0.67 (0.63, 0.70)	0.70 (0.66, 0.74)

*Adjusted for age at referral, specialty volume

†Weighted sample mean is used as reference

Table 3. Hazard ratios for time to scheduling and completing (attending) appointments among children of local primary care clinics referred to a specialty care hospital

	Time to Scheduled Appointment ¹		Time to Completed Appointment ²	
	Unadjusted HR (95%CI)	Adjusted HR (95%CI)*	Unadjusted HR (95%CI)	Adjusted HR (95%CI)**
Race and Ethnicity[†]				
American Indian/Alaska Native	1.09 (1.04, 1.15)	1.08 (1.03, 1.13)	1.04 (0.98, 1.10)	1.05 (0.99, 1.11)
Asian	1.01 (0.99, 1.03)	1.04 (1.02, 1.06)	0.99 (0.97, 1.02)	0.98 (0.96, 1.00)
Black	0.93 (0.91, 0.95)	0.97 (0.94, 0.99)	0.95 (0.93, 0.98)	0.98 (0.95, 1.00)
Hispanic	0.83 (0.81, 0.84)	0.95 (0.94, 0.97)	0.92 (0.91, 0.93)	0.97 (0.95, 0.98)
Multiracial/Other	0.98 (0.96, 1.00)	0.98 (0.96, 1.00)	0.99 (0.97, 1.01)	1.00 (0.98, 1.02)
Native Hawaiian/Pacific Islander	0.94 (0.87, 1.01)	0.96 (0.90, 1.03)	0.90 (0.83, 0.98)	0.94 (0.86, 1.01)
White	1.04 (1.03, 1.04)	1.00 (0.99, 1.01)	1.02 (1.01, 1.03)	1.01 (1.00, 1.02)
Refused	1.08 (1.05, 1.10)	1.06 (1.04, 1.09)	1.07 (1.04, 1.10)	1.06 (1.03, 1.09)
Primary Language				
English	ref	ref	ref	ref
Other	0.60 (0.57, 0.63)	0.68 (0.67, 0.69)	0.82 (0.77, 0.88)	0.93 (0.91, 0.96)
Insurance				
Commercial	ref	ref	ref	ref
Public/Other	0.80 (0.79, 0.81)	0.88 (0.87, 0.89)	0.87 (0.86, 0.88)	0.88 (0.86, 0.89)

[†] Weighted sample mean is used as reference

*Adjusted for age at referral, specialty volume

**Adjusted for age at referral, specialty volume, type of visit (telehealth or in person)

¹ Among referrals that are scheduled

² Among referrals that result in appointment attendance

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