cambridge.org/cty

Original Article

Cite this article: Warren PW, Beck AF, Zang H, Anderson J, and Statile C (2024) Inequitable access: factors associated with incomplete referrals to paediatric cardiology. *Cardiology in the Young* **34**: 428–435. doi: 10.1017/ S1047951122002037

Received: 24 March 2022 Revised: 24 May 2022 Accepted: 14 June 2022 First published online: 18 July 2022

Keywords:

Paediatric; cardiology; referral; health inequity

Author for correspondence:

Paul W. Warren, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, MLC 5018, Cincinnati, OH 45229, USA. Tel: 513-207-9297. E-mail: paul.warren@cchmc.org

© The Author(s), 2022. Published by Cambridge University Press.



Inequitable access: factors associated with incomplete referrals to paediatric cardiology

Paul W. Warren¹⁽¹⁾, Andrew F. Beck^{2,3}, Huaiyu Zang⁴, Jeffrey Anderson^{3,4} and Christopher Statile^{3,4}

¹Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, MLC 2003, Cincinnati, OH 45229, USA; ²General and Community Pediatrics and Hospital Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, USA; ³Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, USA and ⁴Heart Institute, Cincinnati Children's Hospital Medical Center, Cincinnati, USA

Abstract

Objective: To assess the variables associated with incomplete and unscheduled cardiology clinic visits among referred children with a focus on equity gaps. Study design: We conducted a retrospective chart review for patients less than 18 years of age who were referred to cardiology clinics at a single quaternary referral centre from 2017 to 2019. We collected patient demographic data including race, an index of neighbourhood socio-economic deprivation linked to a patient's geocoded address, referral information, and cardiology clinic information. The primary outcome was an incomplete clinic visit. The secondary outcome was an unscheduled appointment. Independent associations were identified using multivariable logistic regression. Results: There were 10,610 new referrals; 6954 (66%) completed new cardiology clinic visits. Black race (OR 1.41; 95% CI 1.22-1.63), public insurance (OR 1.29; 95% CI 1.14-1.46), and a higher deprivation index (OR 1.32; 95% CI 1.08-1.61) were associated with higher odds of incomplete visit compared to the respective reference groups of White race, private insurance, and a lower deprivation index. The findings for unscheduled visit were similar. A shorter time elapsed from the initial referral to when the appointment was made was associated with lower odds of incomplete visit (OR 0.62; 95% CI 0.52-0.74). Conclusion: Race, insurance type, neighbourhood deprivation, and time from referral date to appointment made were each associated with incomplete referrals to paediatric cardiology. Interventions directed to understand such associations and respond accordingly could help to equitably improve referral completion.

Referral to a subspecialty service is a common and necessary occurrence in paediatrics. One-fifth of children are referred to subspecialists annually.¹ The utility of the referral is dependent on completion of the appointment with the subspecialist. Incomplete referrals, those referrals that never result in a visit, are quite common. Of all referrals made to subspecialty clinics among children, an estimated 20–50% are incomplete, with substantial variation across subspecialties.^{2–4}

The American Academy of Pediatrics recommends that children in need of subspecialty care should be seen by a paediatric subspecialist.⁵ And yet, there are several challenges associated with the referral process that have been described in the literature.⁶ Longer wait times and farther distance to in-network subspecialists each decrease the odds of scheduling referral appointments (thereby increasing the rate of incomplete referrals).⁷ Among children, lower perceived necessity by both caregiver and primary care provider is associated with lower referral completion rate.⁸ Challenges including scheduling appointments in a timely manner, inconvenient clinic hours, and difficulty finding clinic locations have also been correlated with higher likelihood of an incomplete referral.³ On the other hand, factors associated with referral completion include younger patient age, private insurance status, and residence within zip codes with higher median income.⁴

There are racial and socio-economic gaps in medical outcomes across subspecialties, including cardiology. It is well documented that Black adults have higher odds of cardiovascular disease and mortality compared to their White peers.⁹ Socio-economic status has also been shown to play a large part in prevalence of out-of-hospital cardiac arrest and cardiovascular disease mortality.^{10,11} Within paediatrics, there is a growing body of evidence demonstrating worse CHD outcomes for infants who are born to mothers identifying as Black, Hispanic, and Asian/Pacific Islander compared to those identifying as non-Hispanic White. Similarly, those living in neighbourhoods with higher poverty rates have suboptimal outcomes compared to those living in neighbourhoods with lower poverty rates. These racial and socio-economic inequities likely emerge from structural factors rooted in differential social determinants of health.¹²⁻¹⁷



It is possible that incomplete referrals, and missed opportunities for the provision of subspecialty services, could negatively affect the patient experience and influence the presence and magnitude of equity gaps in outcomes. While acknowledging that the true positive rate of disease in patients referred to cardiology clinics for common complaints such as chest pain, syncope, and murmur is low,¹⁸⁻²⁰ such symptoms burden patients and their families and referral completion could enhance quality-of-life. Equitable referral completion could do so in ways that narrow gaps.²¹ Still, there has been limited research in paediatrics to evaluate the drivers of incomplete referrals within individual specialties, including paediatric cardiology. The objective of this study was to evaluate the variables associated with incomplete referrals, and inequities in incomplete referrals, among patients referred to paediatric cardiology subspecialty clinics at a quaternary paediatric referral centre.

Materials and methods

Study design and population

We performed a retrospective chart review using data from the Cincinnati Children's Hospital Medical Center paediatric cardiology division. The local institutional review board reviewed and approved this study prior to collecting data. Patients were eligible for inclusion in the dataset if they were referred to paediatric cardiology between January 1, 2017, and December 31, 2019. Referrals were placed by a primary care or subspecialist provider. Eligible patients had to be less than 18 years of age at the time of referral. Patients referred to cardiology within the preceding 3 years were excluded. Patients with missing race/ethnicity, gender, language, health insurance type, and address were also excluded. During the study period, there were no significant changes to the referral process or clinic structure.

Setting

The paediatric cardiology division operates both general paediatric cardiology and cardiology subspeciality clinics. The primary service area for our institution is the Cincinnati metropolitan area. This includes Cincinnati's urban core as well as suburbs and rural areas in Southwest Ohio, Northern Kentucky, and Southeast Indiana. Our cardiology clinics are located throughout the primary service area. There are approximately 23,000 patients seen each year. Referrals can be placed electronically or via fax by a primary care provider or subspecialist provider. Whenever a referral is placed, cardiology staff members call the referred family. If contact is not made on the first call, two additional calls are made over a period of several days. Appointments can be scheduled via these phone calls. For all general cardiology and cardiology subspecialty clinics, wait time is measured using the number of days required to find the 3rd next available appointment. Wait times for general cardiology clinics had a mean 3rd next available appointment of 1.1 days during the study period. However, some of the cardiology subspecialty clinics had wait times that were considerably longer. For example, the time to the 3rd next available appointment was 18.5 days for the hypertension clinic and 44.8 days for the preventive cardiology clinic during the study period.

Key outcome and predictor variables

The primary outcome variable was an incomplete visit following referral to any of the cardiology clinics. Patients were defined as having an incomplete visit if they were referred but never attended a clinic visit, regardless of whether the visit was scheduled. The secondary outcome was an unscheduled appointment. Patients were defined as having an unscheduled appointment if they were referred but never scheduled an appointment. The outcomes were evaluated up until the time of data collection, giving each patient a minimum of two months to schedule and complete their visit before having their visit considered incomplete. Patients were classified as having an appointment scheduled or not scheduled. Of those that were scheduled, they were further classified according to having complete or incomplete visits. We also classified patients as having a complete or incomplete visit regardless of schedule status (Supplementary Table 1).

We evaluated the association between a variety of factors and incomplete/unscheduled referral visits. Patient-level variables included age, race/ethnicity, gender, language, health insurance type, address, and time from referral to appointment (if one was scheduled). These data were all accessible from within the electronic health record. Age was categorised using the distribution among all of those referred, splitting the sample into quantiles. We combined race and ethnicity into a single variable given the ways these variables are assessed across CCHMC and documented within the electronic health record. Race/ethnicity was categorised as Asian, Black, Hispanic/Latino, and White. Gender was classified as male or female. Language was categorised as English, Spanish, or Other. Health insurance was categorised as Private or Public. The patient's address was geocoded and located to a specific census tract geography and related socio-economic data. Specifically, we used a widely available, open-source, validated socio-economic deprivation index. The deprivation index is calculated from census tract-level median household income, fraction of households below the poverty level, fraction of those 25 years and older with at least a high school degree/GED, fraction with insurance, fraction receiving public assistance, and fraction of housing units that are vacant.²² The index ranges from 0 to 1 with higher values representing higher levels of deprivation.²² Census tracts are smaller statistical subdivisions of a county and provide for a more homogeneous population than zip codes allowing for improved study of socio-economic determinants of health.^{23,24} For our analyses, the deprivation index values of comparison were the national mean of 0.38 (slightly higher than our study median of 0.35) and the median of the 5% of patients in our sample living in the most deprived census tracts. We chose to compare the national mean with the most deprived to evaluate the impact of more extreme levels of deprivation on referral completion. For patients in our study living in a census tract with a deprivation index of 0.38, the median income was \$45,000, the poverty level was 15%, and 11% of the population did not have health insurance. For patients in our study living in a census tract with a deprivation of 0.66 (the most deprived 5%), the median income was \$23,000, the poverty level was 48%, and 24% of patients did not have health insurance.

Additional variables included reason for referral and season in which the referral was made. The reason for referral was determined via manual review of the chart by a paediatric cardiologist. We grouped reasons for referral into categories capturing the most common reasons for referral. Categories included abnormal echocardiogram/fetal imaging, abnormal electrocardiogram, evaluations for cardiomyopathy, chest pain, CHD, cyanosis, dizziness/syncope, preventive cardiology, exercise intolerance/dyspnoea, family history, genetic diagnosis, and palpitations (Supplementary Figure 1). The genetic diagnosis category included those patients with a known or suspected genetic



Figure 1. Study Flow Diagram for referrals placed from 2017 to 2019. Completed visit percentage is based off the total number of referrals, including both those who scheduled visits and did not schedule visits.

diagnosis that has increased risk of cardiovascular structural abnormalities or disease. Preventive cardiology included referrals for elevated blood pressures, elevated lipids, and obesity or other metabolic conditions that increase risk of heart disease. The family history category included any patient with concerning family cardiac history including sudden cardiac death, arrhythmias, ischaemic heart disease, and structural abnormalities. Family history of cardiomyopathy, however, was included in the cardiomyopathy category only. If there were multiple referral reasons, the first documented referral reason was used to categorise the referral. Season for referral was grouped into three-month blocks in which the weather conditions are similar for each month in a given block (i.e., December to February in this region is typically cold with occasional snow/ice precipitation).

Statistical analysis

Medians with interquartile ranges for continuous variables (deprivation index and age) and frequencies with percentages for categorical variables were calculated for patient demographic and referral information variables. Bivariate analyses were performed to evaluate differences between patients with complete and incomplete referral visits and patients with scheduled and unscheduled appointments. This was done using the Wilcoxon rank-sum test for continuous variables or chi-square test for categorical variables. Separate multivariable logistic regression models were fitted for incomplete referral clinic visits among all patient with a scheduled visit, incomplete referral clinic visits among all patients (regardless of scheduled or unscheduled visit, Supplementary Table 1), and unscheduled visits using the lrm function in the rms package in R.²⁵ Model predictors included age, race/ethnicity, gender, language, health insurance type, deprivation index, days from referral to appointment scheduled, referral reason, and season of referral. We allowed for potential non-linear associations for age at referral and deprivation index via the inclusion of restricted cubic spline terms (four knots placed at the 5th, 35th, 65th, and 95th percentiles). The probability of incomplete referral or unscheduled visit according to predictors was obtained from the model estimates. Interactions were assessed between predictors; given the lack of significance of such interactions, we opted to remove them from subsequent models. Model discrimination was further measured by the concordance index (c-index). A c-index of value 1 reflects perfect discrimination, whereas 0.5 reflects random prediction. p values less than 0.05 were considered statistically significant. All statistical analyses were performed using R (version 3.6.1).²⁶

Results

There were 12,440 new referrals to paediatric cardiology clinics during the three-year study period. After excluding those with missing variables, there were 10,610 new referrals remaining (Fig 1). Among all referrals, including both those with a scheduled and an unscheduled appointment, 6954 (66%) resulted in a completed cardiology clinic visit. Among all scheduled visits, 79% resulted in a completed visit. Most referrals, 8767 (83%), resulted in a scheduled appointment. The median time from when the referral was placed to when the appointment was scheduled was 20 days; two-thirds (67%) were scheduled within the first 30 days.

The median age of those referred was 9 years (Table 1). Most referrals were for patients who self- or caregiver-identified as White (76%), followed by Black (19%), and Hispanic/Latino (3.2%). This is similar to the racial and ethnic breakdown of Greater Cincinnati²⁷. English was the most common language among those referred (97%). Slightly over half of patients had private insurance (54%) while the remainder had public insurance (46%). The most common referral season was June to August (29%). Most of the referrals were for children living within the primary service area (71%). The most common reason for referral was heart murmur (33%).

Bivariate analysis

Among all scheduled patients who did not complete their referral visit, there was a higher proportion of Black patients (23% versus. 15%, p < 0.001, Table 2), patients with public insurance (53% versus 43%, p < 0.001), and patients referred for preventive cardiology (16% versus 12%, p < 0.001) compared to those who scheduled appointments and completed their cardiology referral visit. In the group of patients that did not schedule an appointment, there was a higher proportion of Black patients (27% versus 17%, p < 0.001, Supplementary Table 2) and patients with public insurance (52% versus 45%, p < 0.001) compared to those who scheduled an appointment.

Regression model for incomplete visits among scheduled referrals

A multivariable logistic regression model was fit to assess incomplete referral clinic visits among all referrals with a scheduled visit as the outcome of interest. The overall likelihood ratio chi-square statistic was 350.10 (degree of freedom = 34, p < 0.001), and the c-index of the model was 0.64. Black patients (OR 1.41; 95% CI

Table 1. Demographics of referred patients

Variable	
Total Referrals	10,610
Gender	
Female	5144 (48%)
Male	5466 (52%)
Race/Ethnicity	
White	8015 (76%)
Black	1977 (19%)
Hispanic/Latino	339 (3.2%)
Asian	279 (2.6%)
Language	
English	10,244 (97%)
Spanish	226 (2.1%)
Other	140 (1.3%)
Insurance type	
Medicaid	4912 (46%)
Private	5698 (54%)
Deprivation Index, median (IQR)	0.35 (0.27, 0.44)
Age at referral, median (IQR)	9.0 (2.0, 14.0)
Age at referral by year	
<1	1549 (15%)
1-6	2730 (26%)
7–12	2574 (24%)
>12	3757 (35%)
Referral reason	
Abnormal echocardiogram/fetal imaging	168 (1.6%)
Abnormal EKG	382 (3.6%)
Cardiomyopathy	142 (1.3%)
Chest Pain	1045 (9.8%)
Congenital Heart Disease	401 (3.8%)
Cyanosis	90 (0.8%)
Dizziness/Syncope	957 (9.0%)
Exercise Intolerance/Dyspnoea	128 (1.2%)
Family History	383 (3.6%)
Genetic diagnosis	308 (2.9%)
Murmur	3451 (33%)
Palpitations	445 (4.2%)
Preventative Cardiology	1613 (15%)
Other	1097 (10%)
Referral season	
December-February	2281 (21%)
- March-May	2454 (23%)
June–August	3081 (29%)
September–November	2794 (26%)

1.22–1.63, Table 2) were more likely than their White peers to not complete their cardiology subspecialty referral. Patients with public insurance (OR 1.29; 95% CI 1.14–1.46) had higher odds of an incomplete referral compared to those with private insurance. Patients living in the most socioeconomically deprived census tracts (deprivation index of 0.68, most deprived 5%) were more likely to not complete their visit compared to those living in census tracts at or below the national deprivation mean (deprivation index of 0.38) (OR 1.32; 95% CI 1.08–1.61). The association between deprivation index and incomplete visit is demonstrated in Figure 2.

Appointments scheduled within the first seven days of the referral being made were less likely to have an incomplete visit (OR 0.62; 95% CI 0.52–0.74) and those taking longer than 30 days to schedule an appointment were more likely to have an incomplete visit compared to those scheduling an appointment within 15–30 days of the referral being placed. Referrals placed from December to February were more likely to have an incomplete visit compared to the reference season of June–August (OR 1.20; 95% CI 1.03–1.39).

Among the referral reasons, abnormal fetal imaging/ echocardiogram (OR 1.62; 95% CI 1.09–2.38), chest pain (OR 1.27; 95% CI 1.01–1.56), CHD (OR 1.60; 95% CI 1.22–2.08), genetic diagnosis (OR 1.93; 95% CI 1.44–2.60), and preventive cardiology (OR 1.42; 95% CI 1.17–1.73) were associated with higher odds of incomplete referral visits compared to the reference referral reason of murmur.

Regression model for incomplete visits among all referrals

A multivariable logistic regression model was fit to assess incomplete referral clinic visits among all referrals, including both scheduled and unscheduled appointments (Supplementary Table 1). The results were similar to the regression model for incomplete visits among referrals with a scheduled visit. Black patients (OR 1.58; 95% CI 1.41–1.77), those with public insurance (OR 1.37; 95% CI 1.25–1.51), and a higher deprivation index (OR 1.34; 95% CI 1.14–1.57) were all associated with higher odds of incomplete visits compared to their White peers, those with private insurance, and those with a lower deprivation index, respectively.

The same referral reasons associated with higher odds of incomplete visit in the model for incomplete visit among scheduled patients were also found to be associated with higher odds of incomplete visit among all referrals and include abnormal fetal imaging/echocardiogram, chest pain, CHD, genetic diagnosis, and preventive cardiology.

Regression model for unscheduled appointments

A separate multivariable logistic regression model was fit to obtain predicted probabilities and ORs for unscheduled appointments. The overall likelihood ratio chi-square statistic was 567.12 (degree of freedom = 29 and p < 0.001), and the c-index of the model was 0.67. Black patients who were referred to cardiology were more likely to have an unscheduled appointment (OR 1.66; 95% CI 1.44–1.90, Supplementary Table 2) while Hispanic/Latino patients were less likely to have an unscheduled appointment (OR 0.63; 95% CI 0.40–0.98) than White patients. Patients with public insurance were more likely to have an unscheduled appointment compared to those with private insurance (OR 1.37; 95% CI 1.21–1.54). There was no clear association between unscheduled appointments and socio-economic deprivation up to the deprivation index of the national mean (0.38); however; patients with a higher deprivation index of 0.66 (the top 5th% most deprived)

Table 2. Variables associated with incomplete visit among scheduled referrals (n = 8767)

Variable	Visit complete ^a	Visit incomplete	p-value ^b	aOR (95% CI) ^c
Total referrals	6954 (79%)	1813 (21%)		
Gender			0.800	
Female	3375 (49%)	872 (48%)		1.00 (0.90; 1.11)
Male	3579 (51%)	941 (52%)		reference
Race/Ethnicity			<0.001	
White	5450 (78%)	1294 (71%)		reference
Black	1065 (15%)	423 (23%)		1.41 (1.22; 1.63)
Hispanic/Latino	239 (3.4%)	60 (3.3%)		1.10 (0.75; 1.63)
Asian	200 (2.9%)	36 (2.0%)		0.73 (0.50; 1.07)
Language			0.700	
English	6697 (96%)	1751 (97%)		reference
Spanish	160 (2.3%)	36 (2.0%)		0.68 (0.41; 1.11)
Other	97 (1.4%)	26 (1.4%)		1.07 (0.67; 1.69)
Median age at referral (IQR)	9.0 (2.0, 14.0)	9.0 (2.0, 14.0)	0.200	1.02 (0.86; 1.20) ^d
Median Deprivation Index (IQR)	0.34 (0.26, 0.43)	0.37 (0.28, 0.46)	<0.001	1.32 (1.08; 1.61) ^e
Insurance type			<0.001	
Medicaid	2991 (43%)	963 (53%)		1.29 (1.14; 1.46)
Private	3963 (57%)	850 (47%)		reference
Referral reason			<0.001	
Abnormal echocardiogram/fetal imaging	114 (1.6%)	38 (2.1%)		1.62 (1.09; 2.38)
Abnormal EKG	280 (4.0%)	54 (3.0%)		1 0.00 (0.72; 1.38)
Cardiomyopathy	71 (1.0%)	24 (1.3%)		1.33 (0.82; 2.18)
Chest pain	782 (9.9%)	208 (9.6%)		1.25 (1.01; 1.56)
CHD	250 (3.6%)	89 (4.9%)		1.60 (1.22; 2.08)
Cyanosis	64 (0.9%)	13 (0.7%)		1.11 (0.60; 2.05)
Dizziness/syncope	644 (9.3%)	134 (7.4%)		1.09 (0.86; 1.37)
Exercise intolerance/dyspnoea	84 (1.2%)	21 (1.2%)		1.59 (0.98; 2.55)
Family history	218 (3.1%)	62 (3.4%)		1.15 (0.84; 1.57)
Genetic diagnosis	164 (2.4%)	78 (4.3%)		1.93 (1.44; 2.60)
Murmur	2544 (37%)	548 (30%)		reference
Palpitations	309 (4.4%)	73 (4.0%)		1.21 (0.91; 1.62)
Preventative cardiology	820 (12%)	296 (16%)		1.42 (1.17; 1.73)
Other	688 (9.9%)	210 (12%)		1.40 (1.16; 1.70)
Referral season			0.110	
Dec-Feb	1448 (21%)	423 (23%)		1.20 (1.03; 1.39)
Jun-Aug	2042 (29%)	521 (29%)		reference
Mar-May	1614 (23%)	393 (22%)		1.00 (0.86; 1.16)
Sep-Nov	1850 (27%)	476 (26%)		1.02 (0.89; 1.18)
Days from referral to appointment scheduled			<0.001	
<7	1508 (22%)	231 (13%)		0.62 (0.52; 0.74)
7-14	1344 (19%)	278 (15%)		0.85 (0.72; 1.01)
15-30	2005 (29%)	493 (27%)		reference
31-60	1286 (18%)	442 (24%)		1.39 (1.20; 1.61)
				(Continued)

Cardiology in the Young

Table 2. (Continued)

Variable	Visit complete ^a	Visit incomplete	p-value ^b	aOR (95% CI) ^c
61-90	386 (5.6%)	166 (9.2%)		1.66 (1.33; 2.06)
>90	425 (6.1%)	203 (11%)		1.82 (1.48; 2.23)

^aValues presented as n (%) unless otherwise specified.

^bp-values calculated using chi-square test or Wilcoxon rank-sum test.

^CAdjusted odds ratio (aOR) and 95% confidence interval (CI) obtained by multivariable logistic regression model for incomplete visits; model adjusted for all the variables listed in the table. ^dAdjusted odds ratio for age at referral calculated comparing age at 75th versus 25th percentile.

eAdjusted odds ratio for deprivation index calculated comparing deprivation index of 0.66 (top 5th% most deprived) to 0.38 (national median).



Figure 2. The probability of incomplete referral (calculated from logistic regression model) is on the y axis and DI is on the x axis. The area shaded grey represents the 95% confidence interval. At increasing levels of deprivation there are higher rates of incomplete visit.

compared to the national mean had increased odds of having an unscheduled appointment (OR 1.22; 95% CI 1.00–1.48, Supplementary Table 2, and Supplementary Figure 2).

Compared to a referral for heart murmurs, cardiomyopathy evaluations (OR 3.87; 95% CI 2.65–5.65), chest pain (OR 1.26; 95% CI 1.02–1.58), CHD (OR 1.69; 95% CI 1.26–2.27), dizziness/syncope (OR 1.55; 95% CI 1.24–1.94), family history (OR 2.56; 95% CI 1.97–3.33), genetic diagnosis (OR 2.09; 95% CI 1.55–2.83), and preventive cardiology (OR 2.91; 95% CI 2.43–3.47) each were associated with higher odds of unscheduled appointments.

Discussion

In this quaternary care paediatric cardiology referral centre, 83% of patients who were referred scheduled an appointment; just 66% of patients completed their referral. The completed referral rate was within the range that has previously been described among children referred to cardiology, although our population size is significantly larger.^{2,4} We found that there were multiple patient-and system-level variables associated with unscheduled and incomplete cardiology clinic visits.

Patient-level variables that were found to be independently associated with unscheduled referral and incomplete visit included Black race and public insurance. This has been established previously in paediatric referrals but not specifically within cardiology.^{2,4,28} Long-standing exploitation of Black Americans

by the medical system has fostered mistrust in the health care system ²⁹. The confluence of mistrust with structural impediments to receipt of health care services disproportionately experienced by minoritised communities is likely influencing this finding.^{30,31} While the research is mixed regarding the effect of patient-provider race, gender, and language concordance on care experiences and clinical outcomes, there has been some evidence that concordance improves patient experience and outcomes.^{32–36} A lack of cardiologists of colour at this institution could similarly influence referral completion rate.

We also found that higher levels of neighbourhood socioeconomic deprivation were associated with unscheduled and incomplete visit. To the best of our knowledge, this has not been previously studied among referred patients to paediatric cardiologists. These findings come at a time when there are growing calls to ensure equitable health care for marginalised populations, including those affected by racial and socio-economic segregation and discrimination.^{37,38} Future efforts to evaluate the barriers mostly commonly encountered by the aforementioned populations to develop targeted interventions and possibly reduce rates of incomplete referral. Moreover, for families struggling to pay rent or put food on the table, an abstract cardiology concern may be a lower priority.

Indeed, competing priorities, rigid work schedules, and transportation challenges all could decrease the ability to schedule and attend an appointment. These factors could also be targets for interventions poised to equitably improve outcomes. For example, alternative approaches to care provision may make sense should transportation emerge as a consistent barrier, as might be suggested by higher rates of incomplete referral during winter months when driving conditions in the service area are more challenging. We are experimenting with the use of a mobile care van and telemedicine, strategies becoming more common in cardiology.^{39,40} E-stethoscope use, in combination with telemedicine, has also proven to be feasible and safe and may be relevant in the evaluation of certain referral reasons (e.g., murmur in a low-risk patient with normal EKG).41-44 Revising the referral process itself might also reduce incomplete visit rates. Prior, just three phone calls were made to the referred patient's family before outreach attempts cease. If a parent works third shift or long hours without breaks during the day, answering calls during business hours may prove impossible. Pursuing a model that triages referrals based on potential or identified risk factors (e.g., living in deprived community, limited transportation options, rigid work schedule) could expedite different outreach strategies. Using the results of this study, we have since revised the referral process by sending an e-mail and letter to referred patients if they do not answer the initial phone calls. They are now also able to schedule appointments via e-mail, and we are currently working on adding the ability to schedule appointments online. Of course, we certainly do not have all the answers. Future qualitative studies including interviews with families who were unable to schedule or attend their visit may help to determine the reasons why visits are not completed. Co-production, that is, identifying solutions with end stakeholders may lead to meaningful, sustainable improvements.

Referrals where a visit was scheduled within 7 days of the referral being placed were associated with lower odds of an incomplete visit. This finding has been previously demonstrated.⁴ This could be caused by higher parental concern or higher acuity/need for cardiology referral. Implementing a process of online referrals with the ability to make an immediate appointment improves attendance of subspeciality clinic visits.⁴⁵ However, blanket implementation of certain interventions, particularly those that involve use of technological innovations, could worsen inequities present in subspecialty access to care.⁴⁶ A careful and targeted roll-out of any intervention would be necessary to track visit completion overall and for marginalised populations.

Among the reasons why patients were referred to our paediatric cardiology clinics, chest pain, CHD, preventive cardiology, and genetic diagnosis all were linked to higher odds of unscheduled appointments and incomplete visits compared to those referred for murmur. Cardiomyopathy and dizziness/syncope clinics had higher odds of unscheduled visits but no difference in the rate at which appointments were completed. There were no data collected from individual referrals on reasons why an appointment was not scheduled or attended. In adults, it has been shown that patients who believed their health problem was resolved could lead to higher odds of incomplete referral.²⁸ This situation is also possible in our population. For example, if a patient is referred for chest pain and the pain resolves prior to making or completing an appointment, chances are the referral will be incomplete.

Adults and children that have a longer wait times until their appointment are less likely to complete their referral.^{7,8} As previously discussed, general cardiology clinics at our institution have shorter mean wait times than subspecialty clinics. This is one possible explanation for why patients referred to preventive cardiology (mean 3rd next available appointment time 44.8 days) had higher odds of unscheduled visit and incomplete referral. Preventive cardiology could have higher incomplete referrals due to differences in perception of the relative importance of the health problem between the referring provider and the referred patient/family which has been previously associated with lower rates of referral completion.⁸ Alternatively, the fear of potential bad news or a negative outcome could affect rates of incomplete referrals for some conditions or chief complaints. For example, parents and adolescent children might fear that attending their cardiology referral visit for chest pain could lead to a need to limit participation in sports. Further research seeking out the parent/ patient perspective on unscheduled or incomplete visits could illuminate specific barriers or challenges and inform innovative, equitable care models.

The variables associated with higher odds of incomplete visit and unscheduled referral were similar across all three multivariable logistic regression models. This suggests that factors that limit one's ability to schedule an appointment may also impair one's ability to complete the visit once it is scheduled. The lack of a difference between these two models (Table 2 and Supplementary Table 1) indicates it might be unnecessary to perform separate analyses in future work comparing odds of incomplete visit among all patients referred versus odds of incomplete visit among referrals with a scheduled visit. Finally, some referrals to paediatric cardiology represent low probability for cardiac pathology.^{18–20,47} These referrals could increase the wait time for patients with a true need for cardiologist evaluation. Partnering with paediatricians to create standardised evaluation, diagnostic, and management plans has been effective in reducing low probability referrals to cardiology while not missing true pathology. ^{48,49} This could decrease wait times for patients with true cardiac pathology.

The results of this study should be evaluated with an understanding of its limitations. First, this study was conducted in a retrospective manner at a single centre. This means that any linkages identified represent association and not causation. Also, there might be geographic, institutional, and specialty differences that limit applicability of the results to other institutions or to other paediatric specialties. Second, the electronic health record data at our disposal did not allow for the determination of why a visit was not scheduled or not attended. For instance, we did not know the parental work schedule, transportation access, distance from the patient's home to specific clinic location where the visit would take place, if certain patients chose to wait longer to visit a clinic location closer to their home, or number of caregivers living within the household. Third, we categorised referrals based on the first reasons for which they were referred if there were multiple reasons for the referral. Therefore, overlap between the different referral reasons may limit the ability to interpret the impact of referral reason on completed cardiology visits. Fourth, the data collection occurred 2 months after the last referral was placed and therefore might limit the ability of those referred in the last month to complete their visit.

Conclusion

Patient- and system-level variables are associated with the rate of cardiology subspecialist referral completion. We need further research to elucidate how we can help our patients more easily complete referrals and receive subspecialty care in equitable ways.

Supplementary material. To view supplementary material for this article, please visit https://doi.org/10.1017/S1047951122002037

Acknowledgements. We thank Nicholas Olberding, PhD, for his statistical assistance. He has no real or perceived conflicts of interest.

Financial support. The study was supported in part by CHD Ohio via a gift of \$2,500 which was used for the statistical analysis. They had no input on study design, implementation, manuscript production, or any other aspect of this publication.

Conflicts of interest. None

References

- Forrest CB, Majeed A, Weiner JP, Carroll K, Bindman AB. Referral of children to specialists in the United States and the United kingdom. Arch Pediatr Adolesc Med 2003; 157: 279–285.
- Zuckerman KE, Cai X, Perrin JM, Donelan K. Incomplete specialty referral among children in community health centers. J Pediatr 2011; 158: 24–30.
- 3. Zuckerman KE, Perrin JM, Hobrecker K, Donelan K. Barriers to specialty care and specialty referral completion in the community health center setting. J Pediatr 2013; 162: 409–14.e1.
- Bohnhoff JC, Taormina JM, Ferrante L, Wolfson D, Ray KN. Unscheduled referrals and unattended appointments after pediatric subspecialty referral. Pediatrics 2019; 144: 1755.

- Basco WT, Rimsza ME, Committee on Pediatric Workforce, American Academy of Pediatrics. Pediatrician workforce policy statement. Pediatrics 2013; 132: 390–397.
- Kunkle EC. Communication breakdown in referral of the patient. JAMA 1964; 187: 663.
- Patel MP, Schettini P, O'Leary CP, Bosworth HB, Anderson JB, Shah KP. Closing the referral loop: an analysis of primary care referrals to specialists in a large health system. J Gen Intern Med 2018; 33: 715–721.
- Zuckerman KE, Nelson K, Bryant TK, Hobrecker K, Perrin JM, Donelan K. Specialty referral communication and completion in the community health center setting. Acad Pediatr 2011; 11: 288–296.
- Van Dyke M, Greer S, Odom E, et al. Heart disease death rates among blacks and whites aged ≥35 years — United States, 1968-2015. MMWR Surveill Summ. 2018; 67: 1–11.
- Jonsson M, Ljungman P, Härkönen J, et al. Relationship between socioeconomic status and incidence of out-of-hospital cardiac arrest is dependent on age. J Epidemiol Community Health. 2020; 74: 726–731.
- 11. Timmis A, Townsend N, Gale CP, et al. European Society of Cardiology: cardiovascular disease statistics 2019. Eur Heart J. 2020; 41: 12–85.
- Wang Y, Liu G, Druschel CM, Kirby RS. Maternal race/ethnicity and survival experience of children with congenital heart disease. J Pediatr. 2013; 163: 1437–42.
- Wang Y, Liu G, Canfield MA, et al. Racial/ethnic differences in survival of United States children with birth defects: a population-based study. J Pediatr 2015; 166: 819–26.e1-2.
- Pace ND, Oster ME, Forestieri NE, Enright D, Knight J, Meyer RE. Sociodemographic factors and survival of infants with congenital heart defects. Pediatrics 2018; 142: 807.
- Lopez KN, Morris SA, Sexson Tejtel SK, Espaillat A, Salemi JL. US mortality attributable to congenital heart disease across the lifespan from 1999 through 2017 exposes persistent racial/ethnic disparities. Circulation 2020; 142: 1132–1147.
- Castellanos DA, Lopez KN, Salemi JL, Shamshirsaz AA, Wang Y, Morris SA. Trends in preterm delivery among singleton gestations with critical congenital heart disease. J Pediatr. 2020; 222: 28–34.e4.
- Nembhard WN, Salemi JL, Ethen MK, Fixler DE, Dimaggio A, Canfield MA. Racial/Ethnic disparities in risk of early childhood mortality among children with congenital heart defects. Pediatrics 2011; 127: e1128–e1138.
- Zavala R, Metais B, Tuckfield L, DelVecchio M, Aronoff S. Pediatric syncope: a systematic review. Pediatr Emerg Care 2020; 36: 442–445.
- Saleeb SF, Li WY, Warren SZ, Lock JE. Effectiveness of screening for lifethreatening chest pain in children. Pediatrics 2011; 128: e1062–e1068.
- Newburger JW, Rosenthal A, Williams RG, Fellows K, Miettinen OS. Noninvasive tests in the initial evaluation of heart murmurs in children. N Engl J Med. 1983; 308: 61–64.
- Anderson JB, Czosek RJ, Knilans TK, Marino BS. The effect of paediatric syncope on health-related quality of life. Cardiol Young 2012; 22: 583–588.
- Brokamp C, Beck AF, Goyal NK, Ryan P, Greenberg JM, Hall ES. Material community deprivation and hospital utilization during the first year of life: an urban population-based cohort study. Ann Epidemiol 2019; 30: 37–43.
- 23. Krieger N, Waterman P, Chen JT, Soobader MJ, Subramanian SV, Carson R. Zip code caveat: bias due to spatiotemporal mismatches between zip codes and US census-defined geographic areas – the Public Health Disparities Geocoding Project. Am J Public Health 2002; 92: 1100–1102.
- Rossiter K. Census Blogs [Internet], 2014 Jul. [cited 2021 Sept 28] Available from:, https://www.census.gov/newsroom/blogs/random-samplings/2014/ 07/understandinggeographic-relationships-counties-places-tracts-and-more. html,
- Harrell FE. rms: Regression Modeling Strategies. R Package Version 6.0-0, 2020, https://CRAN.R-project.org/package=rms, Accessed November 20, 2020,
- 26. Computing RFfS. R: A Language and Environment for Statistical Computing. Vienna, Austria, 2020.
- Census Reporter [Internet]. Illinois, 2019. [cited 2021 October 24]. Available from, https://censusreporter.org/profiles/31000US17140-cincinnatioh-ky-in-metro-area/, Accessed October 10, 2021,
- Forrest CB, Shadmi E, Nutting PA, Starfield B. Specialty referral completion among primary care patients: results from the ASPN Referral Study. Ann Fam Med 2007; 5: 361–367.

- Gamble VN. Under the shadow of Tuskegee: African Americans and health care. Am J Public Health 1997; 87: 1773–1778.
- Bailey ZD, Krieger N, Agénor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. Lancet 2017; 389: 1453–1463.
- 31. Arnett MJ, Thorpe RJ, Gaskin DJ, Bowie JV, LaVeist TA. Race, medical mistrust, and segregation in primary care as usual source of care: findings from the exploring health disparities in integrated communities study. J Urban Health 2016; 93: 456–467.
- Diamond L, Izquierdo K, Canfield D, Matsoukas K, Gany F. A systematic review of the impact of patient-physician non-english language concordance on quality of care and outcomes. J Gen Intern Med 2019; 34: 1591–1606.
- Hsueh L, Hirsh AT, Maupomé G, Stewart JC. Patient-provider language concordance and health outcomes: a systematic review, evidence map, and research agenda. Med Care Res Rev 2021; 78: 3–23.
- 34. Parker MM, Fernández A, Moffet HH, Grant RW, Torreblanca A, Karter AJ. Association of patient-physician language concordance and glycemic control for limited-english proficiency latinos with type 2 diabetes. JAMA Intern Med 2017; 177: 380–387.
- Traylor AH, Schmittdiel JA, Uratsu CS, Mangione CM, Subramanian U. Adherence to cardiovascular disease medications: does patient-provider race/ethnicity and language concordance matter? J Gen Intern Med 2010; 25: 1172–1177.
- Zhao C, Dowzicky P, Colbert L, Roberts S, Kelz RR. Race, gender, and language concordance in the care of surgical patients: a systematic review. Surgery 2019; 166: 785–792.
- 37. Johnson-Agbakwu CE, Ali NS, Oxford CM, Wingo S, Manin E, Coonrod DV. Racism, COVID-19, and health inequity in the USA: a call to action. J Racial Ethn Health Disparities 2020
- Evans MK. Health equity are we finally on the edge of a new frontier? N Engl J Med 2020; 383: 997–999.
- Satou GM, Rheuban K, Alverson D, et al. Telemedicine in pediatric cardiology: a scientific statement from the American Heart Association. Circulation 2017; 135: e648–e78.
- Chowdhury D, Hope KD, Arthur LC, et al. Telehealth for pediatric cardiology practitioners in the time of COVID-19. Pediatr Cardiol. 2020; 41: 1081–1091.
- Belmont JM, Mattioli LF. Accuracy of analog telephonic stethoscopy for pediatric telecardiology. Pediatrics 2003; 112: 780–786.
- Dahl LB, Hasvold P, Arild E, Hasvold T. Heart murmurs recorded by a sensor based electronic stethoscope and e-mailed for remote assessment. Arch Dis Child 2002; 87: 297–301.
- Mahnke CB, Mulreany MP, Inafuku J, Abbas M, Feingold B, Paolillo JA. Utility of store-and-forward pediatric telecardiology evaluation in distinguishing normal from pathologic pediatric heart sounds. Clin Pediatr (Phila) 2008; 47: 919–925.
- Phillips AA, Sable CA, Atabaki SM, Waggaman C, Bost JE, Harahsheh AS. Ambulatory cardiology telemedicine: a large academic pediatric center experience. J Investig Med 2021; 69: 1372–1376.
- 45. Kevat A, Manohar J, Bate N, Harris K. Online referral and immediate appointment selection system empowers families and improves access to public community paediatric clinics. J Paediatr Child Health 2019; 55: 454–458.
- Ray KN, Mehrotra A, Yabes JG, Kahn JM. Telemedicine and outpatient subspecialty visits among pediatric medicaid beneficiaries. Acad Pediatr. 2020; 20: 642–651.
- Dalal NN, Dzelebdzic S, Frank LH, et al. Recurrent cardiology evaluation for innocent heart murmur: echocardiogram utilization. Clin Pediatr (Phila). 2018; 57: 1436–1441.
- Harahsheh AS, Hamburger EK, Saleh L, et al. Promoting judicious primary care referral of patients with chest pain to cardiology: a quality improvement initiative. Med Decis Making. 2021; 41: 559–572.
- 49. Harahsheh AS, O'Byrne ML, Pastor B, Graham DA, Fulton DR. Pediatric chest pain-low-probability referral: a multi-institutional analysis from Standardized Clinical Assessment and Management Plans (SCAMPs[®]), the Pediatric Health Information Systems Database, and the National Ambulatory Medical Care Survey. Clin Pediatr (Phila) 2017; 56: 1201–1208.