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ORIGINAL ARTICLE

WILEY Congenital Heart Disease

Racial disparities in clinic follow-up early in life among survivors of congenital heart disease

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Abstract

Objective: The current study aims to identify the rates of lapses in care and loss to follow-up before age one through age five for white and nonwhite congenital heart disease (CHD) survivors. Nonwhite CHD survivors were hypothesized to experience an earlier lapse in care and be lost to follow-up than whites.

Design: Patients were from a large pediatric hospital and had (1) at least one outpatient cardiology clinic visit or cardiac surgery visit before the age of one and (2) a diagnosis of moderate or complex structural CHD. Cardiology outpatient utilization rates were tracked from before age one through age five. Lapse in follow-up was defined as not having at least one outpatient cardiology visit per year, and loss to follow-up was not returning after a lapse in care by age five. Race was categorized as white and nonwhite. Covariates included sex, insurance type, noncardiology inpatient and outpatient hospital utilization, and CHD severity.

Results: The sample included 1034 patients. Overall, 75.7% experienced a lapse in care with only 41.6% of those returning by age five. Nonwhites experienced lapses in care at younger ages than whites. Nonwhites had a 53% increased risk of lapse in care. Medicaid patients and those with moderate CHD diagnoses also had an increased risk for lapse in care.

Conclusions: Lapse in care appears prevalent among CHD survivors by age five, with nonwhites demonstrating elevated risk. Future multisite prospective studies should include the assessment of parental knowledge, barriers to accessing care, and satisfaction with care.

KEYWORDS
children, clinic follow-up, congenital heart disease, racial disparities

1 | INTRODUCTION

Congenital heart disease (CHD) is the most common congenital birth defect, with approximately seven per 1000 live births having a cardiac anomaly.[1] Due to medical advancements, more than 90% of the individuals born with CHD survive into adulthood, resulting in over one million adults living with CHD in the United States.[2] For these individuals, long-term care is of critical importance. After the period of birth to one year of age, the next highest mortality rates for CHD survivors occur between one and four years of age until older adulthood.[3]

Routine surveillance and follow-up care by a cardiologist is vital for the early detection of cardiovascular deterioration, including arrhythmias and heart failure symptoms, which are among the leading causes of death for adult CHD survivors.[4] However, lapse in care among CHD survivors is common, with as high as 50%-70% not remaining in treatment or being treated by nonadult CHD specialists.[5,6] Being lost to or absent from care is associated with significant cardiac morbidity.[7,8] Loss to cardiovascular follow-up care has been demonstrated to occur among 6-12-year olds, with rates increasing as patients age.[5] Several factors are associated with loss to follow-up care in adulthood, including being male, not having a complex lesion type, and being seen for follow-up care outside a university hospital setting.[5] Rates of loss to follow-up care have not been published for under the age of six, despite the increased risk for mortality in this age group.

Nonwhite ethnicity has also been identified as a predictor of clinic nonattendance for those CHD survivors still engaged in care,[9] but whether racial differences exist for rates of annual cardiology follow-up care over time remains unknown. Racial disparities in CHD have been reported for mortality and morbidity. Black CHD survivors with single ventricle anatomy have a 41% higher mortality rate in comparison to white CHD survivors.[10] Racial disparities in mortality also have been documented for all types of CHD-related surgeries, and these findings persist after controlling for the type of insurance and hospital of surgery.[11] Alarmingly, these disparities continue from infancy into young adulthood,[3] with evidence suggesting that black CHD survivors have an increased risk of readmission after adult CHD surgery.[12] Yet, little research has been directed at identifying the factors contributing to these disparities within the growing population of CHD survivors, including follow-up care.

The current retrospective study sought to determine the rates of lapses in care and loss to follow-up from under the age of one through age five for both white and nonwhite CHD survivors with moderate or complex cardiac lesions after presenting to a children's hospital before one year of age. We hypothesized that nonwhite CHD survivors would have lapses in care at an earlier age and be more likely to not return to care within the study time frame than white CHD survivors.

2 | METHODS

2.1 | Study sample

The cohort was taken from the patient population of a large, urban pediatric hospital in the Midwest and consisted of patients who (1) were seen between 2007 and 2011, (2) before age one had at least one outpatient cardiology clinic visit at the main hospital or a satellite site, or had a cardiac surgery visit, and (3) at such a visit was given a CHD diagnosis of moderate or complex severity.[13] Hospital utilization rates were tracked from baseline (before the age of 1) until age five for all patients. Data were abstracted from electronic medical records. The study procedures were approved by the hospital's Institutional Review Board. Informed consent was not required.

2.2 | Measures

The primary outcome of interest was the age at which patients experienced their first lapse in care of yearly cardiology outpatient clinic follow-ups. Follow-ups were defined as having at least one outpatient cardiology visit (at the main hospital or satellite site) per year, which is appropriate given that the patients identified had CHD lesions that would present for at least yearly follow-up.[14] Age at lapse in care was defined as the first age at which a patient did not have a yearly cardiology follow-up visit up through age five. Loss to follow-up was defined as having a lapse in care with no return to care by the age of five. Our main predictor was race, which was categorized as white and nonwhite (African, black or African American, American Indian and Alaska Native, Asian, Asian Indian, Latino/Hispanic, Native Hawaiian and other Pacific Islander, biracial/multiracial, or other race). Covariates included sex (male or female), insurance type (commercial or Medicaid; 59 people were unable to be categorized due to missing insurance data), noncardiology hospital utilization through age five (number of primary care and emergency department/urgent care visits), and CHD diagnosis severity (moderate or complex). It should be noted that the pediatric hospital and all of its satellite locations accept Medicaid and adhere to a single standard of care. Patients with multiple CHD were classified on the basis of the most complex diagnosis. Patients were excluded from the analyses if they were deceased at any time during the study period or had missing data for race.

2.3 | Plan for analysis

Descriptive statistics included chi-square tests to examine baseline differences in sex, insurance type, and diagnosis severity by racial group, as well as *t* tests to examine racial differences in the number of primary care and emergency/urgent care visits. Survival analysis was conducted to identify the differences in freedom from lapse in cardiology visits by race. Time zero was set at age zero, and follow-ups were tracked through age five. The event was defined as the age at which patients first experience a lapse in cardiology follow-up. Individuals who had follow-up visits at each age were censored at five years.

Kaplan-Meier survival analysis was run with a log-rank test to generate survival curves for whites and nonwhites, estimate survival probabilities for each age through five years, and test for significant differences in the survival curves between races. Cox proportional hazards regressions were run to determine the difference in freedom from lapse in yearly follow-ups for whites and nonwhites. Sex, insurance type, diagnosis severity, and the number of primary and emergency/urgent care visits were added as covariates to the Cox regressions. The proportional hazards assumption of the Cox regression models was tested and found to be met through a visual inspection of the log-log survival curves by using Schoenfeld residuals, and by testing the interactions between the predictors and log (survival time).[15] Data were analyzed with SAS 9.3 (SAS, Cary, North Carolina), and an alpha level of 0.05 was used to determine significance.

3 | RESULTS

The sample included 1034 patients. Before age one, 43.6% had outpatient cardiology visit(s) only, 5.0% had inpatient cardiology visits(s) only, and 51.4% had both outpatient and inpatient visits. For cardiology clinic follow-ups, 81.1% occurred at the main hospital and 18.9% occurred at satellite clinics. Sample demographics, including disease severity, can be seen in Table 1. The sample was mostly white (70.8%) and male (55.4%), and half (49.0%) had Medicaid. White patients were more likely to have private insurance and have fewer emergency/urgent care and primary care visits.

Kaplan-Meier survival analysis with a log-rank test revealed significant differences between the freedom from lapse in care curves for whites and nonwhites ($P < 0.001$). In particular, nonwhites experience a lapse in follow-up at younger ages compared to whites. At all ages, whites had a higher probability of having yearly follow-ups compared to nonwhites (Figure 1). At age one, 67.9% of the whites and 53.0% of the nonwhites had a follow-up visit, but by age five, only 28.1% of the whites and just 14.9% of the nonwhites had at least yearly cardiology follow-ups. Overall, 783 (75.7%) patients in the sample experienced a lapse in yearly follow-up (Figure 2). Of these patients, 326 (41.6%) returned for, on average, 1.6 (SD = 0.8) follow-up cardiology visits by age five. Whites were more likely to return for follow-up than nonwhites ($\chi^2[1, n = 783] = 5.36, P = 0.02$).

Table 2 shows the results from the Cox proportional hazards regressions. In each model, nonwhites had a significantly greater risk for experiencing a lapse in yearly cardiology follow-ups than whites. Nonwhites were 42% more likely to experience a lapse in follow-up care in the univariate model (model 1). The hazard ratio for race continued to be significant after being sequentially adjusted for covariates (models 2-4). In the subsequent multivariate models, sex and insurance type were adjusted for first (model 2), then diagnosis severity was added (model 3), and finally the number of primary care visits and the number of emergency department/urgent care visits were included (model 4). With the exception of the number of primary care visits and sex, all of other the covariates were significant predictors and the hazard ratio for a particular covariate remained nearly identical in each model. In the final model (model 4), nonwhites had a 53% increased risk of a lapse in follow-up care, and Medicaid patients were 22% more likely to have a lapse in yearly follow-ups. In addition, patients with moderate CHD diagnoses were more than twice as likely to experience a lapse in yearly cardiology clinic visits as those with a complex lesion. Finally, for each increase in the number of emergency department and urgent care visits, the hazard rate decreased by 2% for having a lapse in yearly follow-ups.

TABLE 1 Study cohort characteristics by race ($N = 1034$)

	White	Nonwhite	
	n (%) or *M* (SD)	*n* (%) or *M* (SD)	*P* value
Total	732 (70.8)	302 (29.2)	
Sex			
Female	323 (44.1)	138 (45.7)	0.644
Male	409 (55.9)	164 (54.3)	
Insurance type			
Commercial	385 (55.8)	83 (29.1)	<0.001
Medicaid	305 (44.2)	202 (70.9)	
Diagnosis severity			
Moderate	549 (75.0)	238 (78.8)	0.192
Complex	183 (25.0)	64 (21.2)	
#PC visits[a]	1.0 (4.8)	8.8 (10.8)	<0.001
#ED/UC visits[a]	2.8 (4.3)	7.6 (9.6)	<0.001

Abbreviations: ED, emergency department; PC, primary care; UC, urgent care.

[a] Visits ages 0-5.

4 | DISCUSSION

This is the first study to characterize lapse in follow-up care among CHD survivors early in life by race and other factors. Our findings suggest that experiencing a lapse in yearly follow-up care is prevalent among CHD survivors by the age of five for all races, with nonwhites demonstrating an elevated risk for a lapse in follow-up. This is also the first study to document that nonwhites are at greater risk for loss to follow-up care during the first five years of life. Research on loss to follow-up care within CHD has primarily focused on transitioning to adulthood (12-22 years of age) with guidelines recommending that the transfer of care from a pediatric cardiologist to an adult CHD specialist occur early in adulthood.[13,16] Gaps in care so soon after diagnosis early in life may contribute to poor outcomes, especially among nonwhite CHD survivors. After the period of birth to one year of age, the next highest mortality rates for CHD survivors occur between one and four years of age until older adulthood,[3] making the current findings particularly alarming.

Unequal access to care has been proposed as an explanatory factor for racial and ethnic differences in mortality from cardiac surgery among children with CHD, which is only partly explained by insurance type.[17] The current study demonstrates that insurance likely plays a role in experiencing a lapse in yearly follow-up, but does not account for the racial/ethnic differences identified. Within the acquired heart disease literature, support has grown for the impact of patient-provider relationships on racial and ethnic disparities in quality of care and offered treatments, above and beyond issues regarding access to care.[18,19] Racial and ethnic differences in perceptions of patient-provider relationships should be examined as effect modifiers in future prospective studies on loss to follow-up care among CHD survivors.

Protective factors for loss to follow-up care have also been suggested among older children and young adult CHD survivors, including a higher family income and undergoing cardiac catheterization in the past 5 years.[20] In the current study, insurance type was used as a proxy for family income, with Medicaid likely representing families with lower income as compared to those families with private insurance. Using self-reported family income would have offered greater variability to allow examination of income as a protective

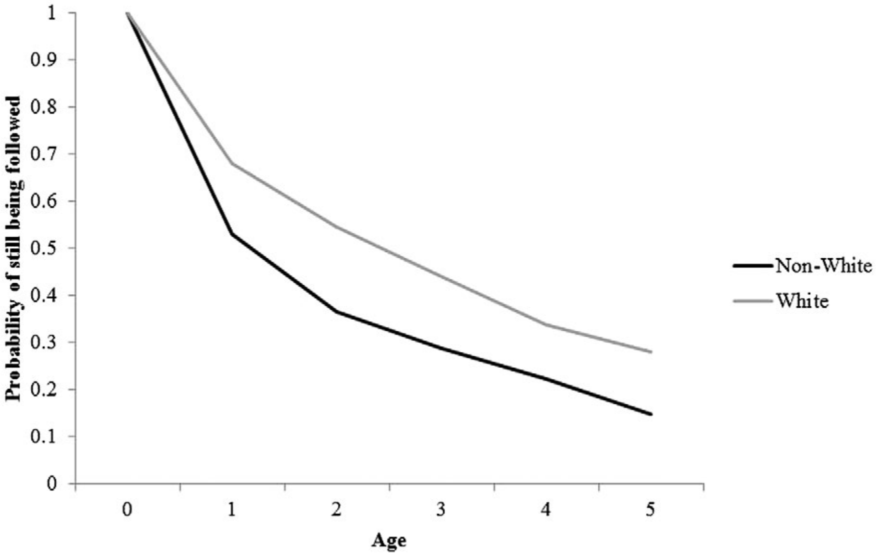

FIGURE 1 Probability of consistent yearly cardiology follow-ups before age one through age five stratified by race. Nonwhites were lost to follow-up at younger ages compared to whites. (Kaplan-Meier analysis with log-rank test, $P < .0001$)

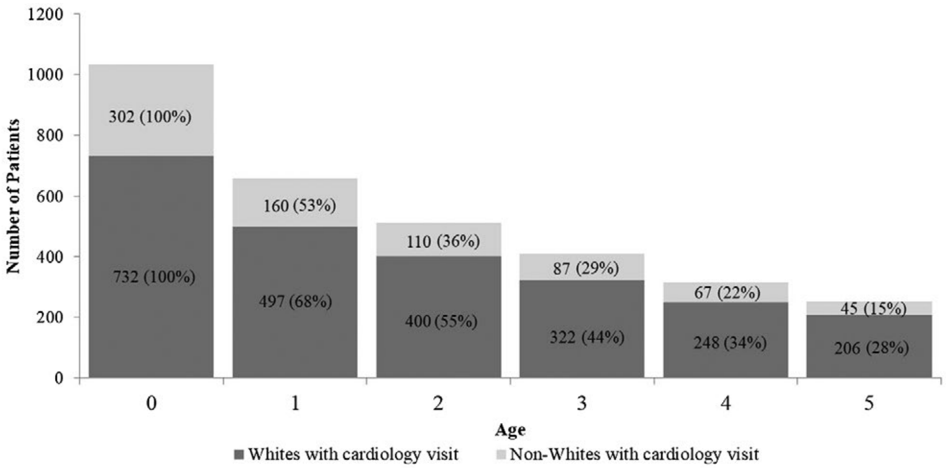

FIGURE 2 Number (and percentage) of patients with consistent annual cardiology follow-ups before age one through age five by race

TABLE 2 Cox proportional hazards models: predictors of lapses in yearly cardiology follow-ups

	Model 1		Model 2		Model 3		Model 4	
Predictors	**HR (95% CI)**	***P* value**	**HR (95% CI)**	***P* value**	**HR (95% CI)**	***P* value**	**HR (95% CI)**	***P* value**
Nonwhite	1.42 (1.22-1.64)	<0.001	1.37 (1.16-1.60)	<0.001	1.36 (1.16-1.59)	<0.001	1.53 (1.28-1.82)	<0.001
Female	...	...	1.13 (0.98-1.31)	0.106	1.14 (0.98-1.31)	0.106	1.12 (0.97-1.30)	0.119
Medicaid	...	...	1.14 (0.98-1.33)	0.085	1.16 (1.00-1.35)	0.049	1.22 (1.04-1.42)	0.014
Moderate severity	...	...	...	...	2.03 (1.68-2.47)	<0.001	2.02 (1.66-2.45)	<0.001
#PC visits[a]	...	...	...	...	...	...	1.00 (0.99-1.01)	0.787
#ED/UC visits[a]	...	...	...	...	...	...	0.98 (0.96-0.99)	<0.001

Abbreviations: CI, confidence interval; HR, hazard ratio; ED, emergency department; PC, primary care; UC, urgent care.
[a] Visits ages 0-5.

factor, given that the income of families with private insurance varies widely.[21] Catheterizations may be considered indications of disease severity, given that CHD survivors who have more complex lesions would also receive more cardiac catheterizations to monitor cardiac function. Therefore, based on the findings by Mackie and colleagues,[20] those with more complex disease who likely require more monitoring may be at a lower risk for loss to follow-up. Similar principles may apply to the current study, such that those who do not require as much regular testing and monitoring (ie, moderate disease severity) may be less likely to be consistently engaged in care. Of note, disease severity carried the highest risk for lapse in yearly follow-up care of the variables examined.

5 | LIMITATIONS

The current study had several limitations. First, the duration of follow-up available was constrained due to when the electronic medical records system came online in 2007. A longer period of follow-up would allow better identification of if and when patients who were lost to follow-up care by the age of five returned to the hospital or satellite clinic later in life. Despite this limitation, the current study highlights the high prevalence of lapses in care at a much earlier age than has previously been examined with only 41.6% of those who did not have consistent yearly follow-ups returning for another cardiology appointment through age five. Second, what was considered a lapse in care may not have been a true lapse given that some follow-up appointments may have been scheduled beyond the one-year window for the current study due to clinic availability or to better coincide with the academic year for children. The current study reported on the number of survivors who returned to care within the study time frame, which would account for those who had a follow-up appointment outside the yearly window, and racial differences persisted. Third, due to the retrospective nature of the study, reasons for lapses in cardiology appointments were not measured. For example, families may have moved or followed up with a pediatric cardiologist not associated with the hospital, or families may not have been satisfied with their care. Other factors of potential importance that could be abstracted from medical records were included in the analyses (ie, sex, insurance type, lesions severity, and other types of visits in the hospital system). However, additional factors also would be important to ascertain, including parental education level, barriers to transportation, parent knowledge about the need for continued care, and satisfaction with care. Fourth, the sample size for nonwhites did not allow for further delineation by race and ethnicities. This prevented the examination of patterns in lapses in care that may differ between blacks, Hispanics, Asians, and other racial and ethnic groups. Fifth, while the current hospital has a large catchment area that is racially and ethnically diverse, ideally the findings could be replicated in other medical centers across the country. A multisite study would also provide a larger sample size that could allow for the examination of follow-up patterns across different races and ethnicities.

6 | CONCLUSIONS

The current study demonstrates that the initial lapse in care experienced by CHD survivors with moderate or complex lesions is likely to occur by the age of five. This may suggest that education about the importance of regular engagement in care is needed at the point of diagnosis and/or surgical intervention, particularly for those with less complex forms of CHD who also need lifelong care.[22] Further focus on which factors may be contributing to lapses in follow-up care is necessary, which would provide critical information for formulating interventions. For example, better understanding parents' attitudes regarding the need for follow-up could inform a behavioral economic approach to encouraging engagement in care and surveillance, as has been demonstrated in cancer screening among underserved populations.[23] Nonwhite patients may also be receiving differential care, including being provided with less education about the importance of follow-up, or may report less satisfaction with their care. Special attention should be given to better understanding the cultural differences in attitudes toward follow-up care, barriers to remaining engaged in care, and satisfaction with the quality of care for CHD.

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CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

Concept/design: Jackson, Daniels, and Chisolm
Data collection: Harris and Morack
Statistics: Morack
Drafting article: Jackson, Morack, Harris, and DeSalvo
Critical revision of article: Chisolm and Daniels

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