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#### **ORIGINAL ARTICLE**

# Clinic nonattendance is associated with increased emergency department visits in adults with congenital heart disease

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## Abstract

Objective: To determine the prevalence and predictors of nonattendance in an ACHD outpatient clinic, and to examine the relationship between nonattendance and emergency department (ED) visits, hospitalizations, and death.

Methods: Patients ≥ 18 years who had scheduled appointments at an ACHD outpatient clinic between August 1, 2014 and December 31, 2014 were included. The primary outcome of interest was nonattendance of the first scheduled appointment of the study period, defined as "no-show" or "same-day cancellation." Secondary outcomes of interest were ED visits, hospitalizations, and death until December 2017.

Results: Of 527 scheduled visits, 55 (10.4%) were nonattended. Demographic and socioeconomic characteristics such as race, income, and insurance type were associated with non-attendance (all P values < .05), whereas age, gender, and disease complexity were not. On multivariable analysis, predictors of nonattendance were black race (adjusted odds ratio [AOR] 4.95; P < .001), other race (AOR 3.54; P = .003), and history of no-show in the past (AOR 4.95; P < .001). Compared to patients who attended clinic, patients with a nonattended visit had a threefold increased odds of multiple ED visits and a significantly lower rate of ED-free survival over time. There were no significant differences in hospitalizations or death by attendance.

**Conclusions:** ACHD clinic nonattendance is associated with race and prior history of no-show, and may serve as a marker of higher ED utilization for patients with ACHD.

#### **KEYWORDS**

adult congenital heart disease, emergency department, outcome

## **1** | INTRODUCTION

Nonattendance in outpatient clinic is a common problem across all medical specialties. In addition to reducing clinic efficiency and increasing waitlist times, nonattendance has been associated with adverse clinical outcomes in chronic disease.<sup>1-3</sup> It has been recently demonstrated that clinic nonattendance is associated with decreased survival for patients with adult congenital heart disease (ACHD).<sup>4</sup> Guidelines recommend routine follow-up at specialized

ACHD clinics but it is not known whether clinic nonattendance is associated with other adverse outcomes among ACHD patients.

Insight into the relationship between clinic attendance and patient outcomes may help reduce the health care burden of this growing population. There has been a steady increase in health care utilization by ACHD patients over the last two decades, with rising numbers of costly ED visits and hospitalizations.<sup>5-8</sup> Between 1998 and 2005, there has been a progressive increase in the number of emergency department visits in the United States by ACHD

patients,<sup>5</sup> and the number of hospital admissions has more than doubled.<sup>6</sup> Appointment nonadherence in primary care clinics has been shown to predict increased emergency department visits and hospitalizations,<sup>9,10</sup> but this has yet to be explored in ACHD tertiary care.

We hypothesize that due to poor continuity of care, it is possible that patients who do not attend ACHD clinic appointments have higher rates of ED visits and hospital admissions compared to those who do attend their scheduled outpatient visits. If this association exists, knowing patient and clinical characteristics associated with outpatient nonattendance may help clinicians identify at-risk patients and mitigate such adverse outcomes.

The objectives of this study were to (1) to determine the prevalence of nonattendance in an ACHD outpatient clinic; (2) identify the demographic and clinical factors associated with nonattendance in this population; and (3) examine the relationship between nonattendance and ED visits, hospitalizations, and death.

#### 2 | METHODS

#### 2.1 | Study population

This was a retrospective study of patients 18 years or older who had scheduled appointments in the Philadelphia Adult Congenital Heart Center outpatient clinic between August 1, 2014 and December 31, 2014. Data were collected through electronic medical record review including clinical, demographic, and visit characteristics. The appointments themselves were subcategorized as either "new patient" or "return patient" visits. "Non-attendance" of the scheduled appointment was defined as "no-show" or "same day cancellation." "No-show" was defined as an unattended visit in which the patient did not notify the clinic to cancel, while "same day cancellations" included unattended visits which were canceled on the day of the appointment. For patients with multiple appointments during the study period, only the first visit was included in the study.

Adverse outcomes were ED visits, hospitalizations, and death which were recorded by chart review for all patients between August 1, 2014 and December 31, 2017. Data were collected through electronic medical record review and captured records of ED visits and hospitalizations that occurred within the University of Pennsylvania Health System. The primary reason for each encounter was determined from review of the discharge summary note. Scheduled hospital admissions (ie, pacemaker lead revisions, elective procedures, initiation of antiarrhythmic therapy) and hospital encounters lasting <24 hours were excluded.

Patients were grouped by congenital heart disease complexity (CHD) according to the 32nd Bethesda Conference classification.<sup>11</sup> Median household income by zip code was recorded using census data from Social Explorer (US Census Bureau).<sup>12</sup> Insurance type was classified as private vs government, with government-sponsored insurance defined as Medicaid, Medicare, and TRICARE plans. Written informed consent was waived and the study was approved by the institutional review board at the Hospital of the University of Pennsylvania.

## 2.2 | Statistical analysis

Statistical analysis was performed using SAS version 9.4 (SAS Institute) and SPSS version 23 (IBM Corp., Armonk, NY, USA). Categorical variables are presented as count (percentage) and continuous variables are presented as median and interquartile range (IQR).

Comparisons of clinical, demographic, and visit characteristics by attended visits and nonattended visits were performed using Chi-square and Wilcoxon rank-sum tests. To test the impact of each covariate on the odds of visit nonattendance, univariate logistic regression models were used to calculate an odds ratio and a 95% confidence interval (Cl). Statistically significant variables had a P value less than 0.05 and a 95% Cl that did not include 1. Variables with P value < 0.2 in the univariate models were selected to assemble a preliminary multivariable model. After backward stepwise regression was performed, all factors associated with nonattendance with P < 0.05 were retained in the final multivariable model.

Chi-square, Fisher's exact, and Wilcoxon Rank-Sum tests were used to assess the relationship between nonattendance and adverse outcomes, where counts of ED visits and hospitalizations were observed as binary group variables using two different cut points (0 visits vs at least 1 visit and 0-1 visits vs 2 or more visits). Next, univariate logistic regression models were used to calculate odds ratios and 95% CIs to assess the impact of attendance on binary ED visits, hospitalizations, and death. Finally, an additional exploration of ED visits and hospitalization used survival analysis methods to observe time to ED visit and time to hospitalization. Follow-up time began at the date of each patient's scheduled clinic visit, which was either attended or nonattended. Outcomes occurring prior to the date of scheduled visit were excluded. For both outcomes, we assumed complete follow-up from start date until the occurrence of an ED visit, hospitalization, or the end of study period (December 31, 2017). Kaplan-Meier product-limit estimates stratified by clinic attendance were used to find estimates of ED visit and hospitalization rates at 12 months, 24 months, and 36 months. Log-rank tests were used to compare the time to outcome by attendance (attended vs nonattended). Cox Proportional Hazards models examined the risk of outcome based on clinic attendance.

### 3 | RESULTS

There were a total of 527 scheduled visits (unique patients) in the analysis, of which 55 (10.4%) were nonattended. Of the nonattended visits, 13 (2.5%) were same-day cancellations and 42 (8.0%) were no-shows. Only 1% (n = 6) of patients attended the first visit but did not attend a subsequent visit up to December 31, 2014. Table 1 summarizes the characteristics of the patients and scheduled visits. Nonwhite race (P < .001), Philadelphia residency (P < .001), shorter driving distance (P = .005), lower median household income (P < .001), government-sponsored insurance (P = .001), lack of primary care physician (P = .03), and history of no-show within the past

#### **TABLE 1** Clinical, demographic, and visit characteristics of patient population (N=527)

Variable	Total	Attended	Nonattended	P-value
Patient characteristics				
Age, years (Median, IQR)	32 (25.0-42.0)	34.8 (25.0-43.0)	32.5 (24.0-38.0)	0.18
Female	284 (53.9%)	255 (54.0%)	29 (52.7%)	0.89
Race				<0.001
White	384 (72.9%)	361 (76.5%)	23 (41.8%)	
Black	80 (15.2%)	58 (12.3%)	22 (40.0%)	
Other <sup>a</sup>	63 (12.0%)	53 (11.2%)	10 (18.2%)	
Married	177 (33.6%)	161 (34.1%)	16 (29.1%)	0.51
Tobacco use (N = 526)	33 (6.3%)	30 (6.4%)	3 (5.5%)	1.00
Alcohol use (N = 523)	309 (59.1%)	282 (60.3%)	27 (49.1%)	0.11
Drug use (N = 509)	27 (5.3%)	22 (4.8%)	5 (9.6%)	0.18
Median household income (\$K) <sup>b</sup>	69.7 ± 27.7	71.8 ± 26.8	54.4 ± 28.1	<0.001
Insurance (N = 520)				0.001
Private	386 (74.2%)	358 (76.5%)	28 (53.8%)	
Government-sponsored <sup>c</sup>	134 (25.8%)	110 (23.5%)	24 (46.2%)	
Has a primary care physician	487 (92.4%)	441 (93.4%)	46 (83.6%)	0.03
Philadelphia resident	113 (21.4%)	87 (18.5%)	26 (47.3%)	<0.001
Disease complexity <sup>d</sup>				0.18
Mild	81 (15.4%)	74 (15.7%)	7 (12.7%)	
Moderate	247 (46.9%)	226 (47.9%)	21 (38.2%)	
Severe	169 (32.1%)	149 (31.6%)	20 (36.4%)	
Other	29 (5.5%)	23 (4.9%)	7 (12.7%)	
CHD diagnosis				0.88
Tetralogy of fallot	102 (19.4%)	92 (19.5%)	10 (18.2%)	
Fontan	58 (11.0%)	51 (10.8%)	7 (12.7%)	
D-TGA	53 (10.1%)	48 (10.2%)	5 (9.1%)	
Aortic coarctation	48 (9.1%)	46 (9.7%)	2 (3.6%)	
BAV/aortic stenosis	37 (7.0%)	34 (7.2%)	3 (5.5%)	
Ventricular septal defect	29 (5.5%)	24 (5.1%)	5 (9.1%)	
Pulmonary stenosis	24 (4.6%)	23 (4.9%)	1 (1.8%)	
AVC	22 (4.2)	18 (3.8%)	4 (7.3%)	
L-TGA	20 (3.8%)	18 (3.8%)	2 (3.6%)	
Atrial septal defect	18 (3.4%)	13 (2.8%)	5 (9.1%)	
Other	116 (22.0%)	105 (22.2%)	11 (20.0%)	
Visit characteristics	,	, , ,	,,	
Visit type				0.95
New patient visit	148 (28.1%)	132 (28.0%)	16 (29.1%)	
Return patient visit	379 (71.9%)	340 (72.0%)	39 (70.9%)	
History of no-show (within past 3 years)	69 (13.1%)	48 (10.2%)	21 (38.2%)	<0.001
Driving distance, miles (median, IQR)	27.0 (11.5-52.9)	27.7 (12.8-53.3)	16.0 (6.0-45.0)	0.005

<sup>a</sup>Other race includes: Asian, Hispanic, Other, Unknown.

<sup>b</sup>Median household income by zip code obtained from census data from Social Explorer©.

<sup>c</sup>Government-sponsored insurance is defined as Medicaid, Medicare and TRICARE plans.

<sup>d</sup>Disease complexity as defined by 32<sup>nd</sup> Bethesda Conference.

3 years (P < .001) were more frequently observed in nonattended visits compared to attended visits, whereas age, gender, marital status, substance use, CHD diagnosis, and visit type were not.

On univariate logistic regression analysis, variables associated with nonattended visits were black or "other" nonwhite race (Hispanic, Asian, other, unknown), Philadelphia residency, government-sponsored insurance, lower median household income, lack of primary care physician, prior history of no-show and "other" disease complexity (Figure 1). In a final multivariable model, race and history of no-show emerged as the most predictive covariates of nonattendance (Figure 2). Compared to patients of white race, patients of black race had nearly a 5-fold higher odds of nonattendance (P < .001), whereas patients of other nonwhite race had a 3.5-fold higher odds of non-attendance (P = .003). Patients with a prior history of no-show had a nearly fivefold higher odds of nonattendance (P < .001) vs those who attended their outpatient ACHD clinic visit.

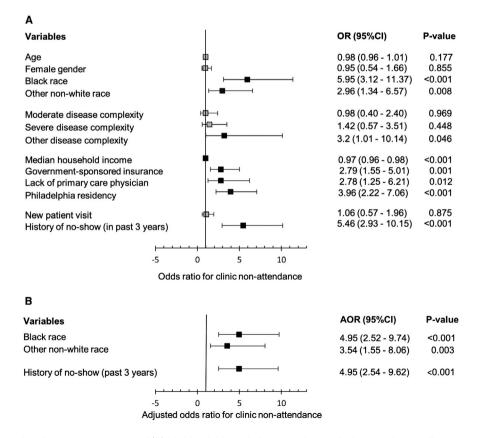
Between August 1, 2014 and December 31, 2017, 103 (19.5%) patients visited the ED, 99 (18.8%) patients were admitted to the hospital, and 10 (1.9%) patients died. There were a total of 245 ED visits and 208 hospitalizations, of which 80 (38.5%) originated from the ED. Figure 3 demonstrates the primary reasons for ED visits and hospitalizations. Nearly half of all visits had cardiac-related reasons, with 40.8% of ED visits and 45.2% of hospitalizations occurring for cardiac symptoms. Chest pain, congestive heart failure, and arrhythmias were the most common primary reasons for ED visits.

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Congestive heart failure, pregnancy, and arrhythmia were the most common primary reasons for hospitalizations. Of the 80 hospital admissions that originated from the ED, the most common admitting diagnoses were congestive heart failure (26.3%), arrhythmia (15.0%), and infection (10.0%). The most common diagnoses for patients who visited the ED without a hospital admission were chest pain (19.9%), "other" noncardiac reasons (16.9%), and infection (11.4%).

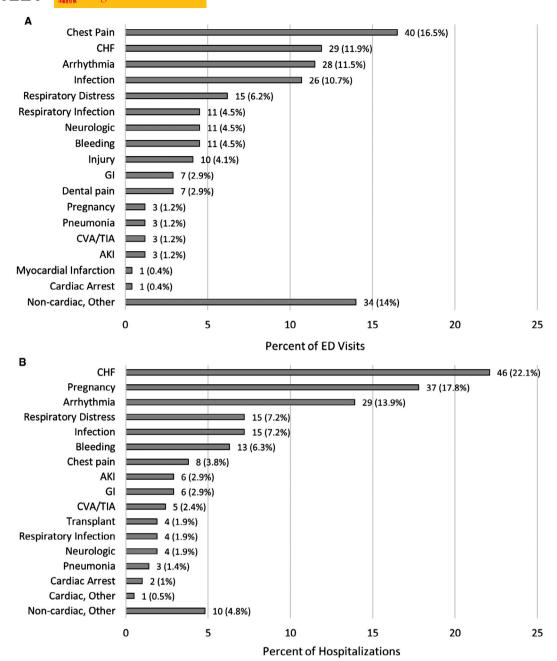
Patients who had nonattended clinic visits trended toward higher prevalence of ED visits than those who attended clinic (29% vs 18%, P = 0.059). However, this difference was significant when ED visits were defined as at least two or more (18% vs 7%, P = .009). Univariate logistic regression analysis showed that compared to patients who attended clinic, patients with a nonattended visit had a threefold increased odds of having two or more ED visits up to 3 years postappointment (confidence interval [CI] 1.4–6.4; P = .006). There were no significant differences in hospitalizations or death between patients who attended or not. Even when planned admissions for pregnancy were excluded, no significant differences in hospitalization were observed.

Kaplan-Meier analyses of the groups stratified by nonattendance or attendance for ED visits and hospitalizations are shown in Figure 3. When observing time from scheduled appointment, there was a significantly higher freedom from ED visits at 12, 24, and 36 months for those who attended clinic compared to those who did not (Figure 3A). There was an increased risk of an ED visit for those who did not attend clinic with Hazard Ratio (HR) 2.07 (95%



**FIGURE 1** (A) Univariate logistic regression and (B) Multivariable logistic regression analysis assessing predictors of outpatient clinic nonattendance among ACHD patients

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**FIGURE 2** Primary reasons for (A) ED visits and (B) hospitalizations among patients with ACHD. Abbreviations: ACHD, adult congenital heart disease; AKI, acute kidney injury, CHF, congestive heart failure, CVA, cerebrovascular accident, GI, gastrointestinal, TIA, transient ischemic attack

Cl, 1.20–3.56; P = .008). There was a higher freedom from hospitalization for those who attended clinic compared to those who did not, but this did not reach significance (Figure 3B). Likewise, risk of a hospitalization was for those who did not attend clinic compared to those who did attend did not reach statistical significance with HR 1.60 (95% Cl, 0.93–2.76; P = .084).

### 4 | DISCUSSION

Our study evaluated the predictors of nonattendance at an ACHD outpatient clinic and explored associations with adverse outcomes.

We found that the prevalence of nonattendance in an ACHD clinic was 10.4%. Nonattendance at ACHD clinic was associated with lower household income, use of government-sponsored insurance, lack of primary care physician, shorter driving distance, and Philadelphia residency. On multivariable analysis, black and nonwhite race as well as a history of no-show in the past emerged as significant predictors of nonattendance. Clinic nonattendance itself was associated with multiple ED visits but not with hospitalization or death.

While there is a growing body of literature on nonattendance in primary care and other specialty clinics, there is a paucity of data on nonattendance in the ACHD population. As both the rate and predictors of nonattendance vary considerably across specialties,<sup>13</sup>

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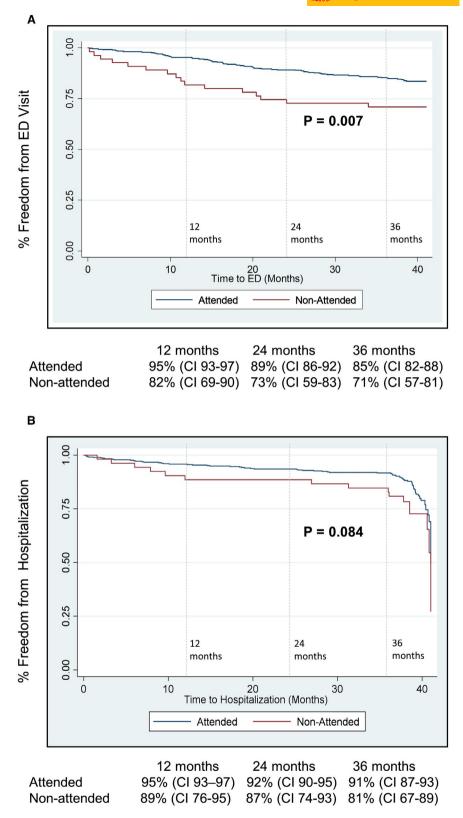


FIGURE 3 Kaplan-Meier curves for (A) ED-free survival and (B) hospitalization-free survival for patients with attended (Blue) vs nonattended (Red) clinic visits

a closer look into the ACHD population is merited. Kempny and colleagues have published the only study to date examining nonattendance in an ACHD outpatient clinic in the United Kingdom in which the prevalence of nonattendance was 23.4%.<sup>4</sup> Similar to our study, the authors identified non-Caucasian ethnicity, lower socioeconomic status, and number of previous clinic nonattendances as – 🚮 Congenital Heart Disease

significant predictors of clinic nonattendance. Associations between nonattendance, race, and socioeconomic status have been widely observed in both primary care clinics and specialty clinics, commonly attributed to financial and transportation barriers to care among other reasons.<sup>14-16</sup> We observed an inversed correlation between nonattendance and greater driving distance as well as a significant association between nonattendance and Philadelphia residency. Similarly inversed relationships between proximity and appointment adherence have been observed in other inner city specialty clinics, potentially due to greater income inequality within metro populations.<sup>14,17,18</sup>

Notably, we did not observe a relationship between disease severity and clinic attendance. Prior studies have shown that adults with severe CHD lesions are more likely to seek cardiology care, with higher rates of follow-up and fewer gaps in care.<sup>19,20</sup> Yet, like Kempny et al., we found that for patients within established care, disease severity was not associated with appointment adherence. Our results suggest that factors influencing loss to follow-up may be distinct from those impacting clinic attendance. We surmise that there are unmeasured barriers to care that may prevent patients from attending scheduled clinic visits, regardless of disease severity.

In our analysis, black race and a history of no-show in the past were the strongest independent predictors of clinic nonattendance. Income, while significantly associated with nonattendance, was excluded from the multivariable model due to collinearity with race. Racial disparities in cardiovascular disease outcomes have been widely observed, and research has identified differences in system-level factors, such as low socioeconomic status, as well as patient-level factors, such as medication nonadherence.<sup>21,22</sup> Evidence from HIV clinics suggests that reducing the racial disparities in clinic nonattendance may help diminish the racial disparities seen in clinical outcomes.<sup>23,24</sup> ACHD patients from minority and underserved populations should be considered at risk for clinic nonattendance and warrant concerted attention from clinicians. If instances or patterns of nonattendance are noted in these patients, additional efforts should be taken to understand the behavior and encourage attendance. However, while our results have identified a vulnerable population, this consideration ultimately applies to patients of all backgrounds. Consistent with the majority of no-show studies, our findings show that the most reliable predictor of nonattendance is a history of no-show in the past.<sup>13</sup>

In general, scheduled monitoring in an appropriate clinical setting is thought to lead to improved outcomes for patients with chronic disease.<sup>1-3</sup> Current guidelines for the management of patients with ACHD recommend routine follow-up at specialized ACHD centers.<sup>25</sup> Evidence supports these guidelines, with one study demonstrating that increased referral rates to specialized ACHD care were accompanied by a significant reduction in ACHD patient mortality.<sup>26</sup> Other researchers have shown that patients with a lapse in tertiary ACHD care have been shown to exhibit worse symptoms and a greater need for urgent cardiac intervention.<sup>27</sup> Most recently, nonattendance of scheduled ACHD clinic visits was found to be an independent predictor of mortality.<sup>4</sup> Our study demonstrates for the first time that ACHD clinic nonattendance is a significant predictor of increased ED utilization. Patients with nonattended clinic appointments not only had a greater risk of ED visit, but they were also significantly more likely to experience multiple ED visits compared to patients who kept their appointments. While increased ED utilization is often attributed to nonurgent replacement for primary care,<sup>28-30</sup> the most common ED visit reasons in our patient population were chest pain, heart failure, and arrhythmia. These urgent cardiac complaints are consistent with a nationwide study of ED use among ACHD patients and are particularly important given the increasing burden in ED utilization among patients with ACHD.<sup>5</sup>

Multiple mechanisms may account for this association. One explanation is that patients who miss appointments receive delayed cardiac care, increasing the likelihood of otherwise preventable health crises and ED visits. For ACHD patients, a healthy, proactive approach to care involves regular attendance at a specialized outpatient clinic, where timely treatments can be prescribed based on subtle changes observed from routine tests. In contrast, patients with a reactive approach to care rely on an escalation of symptoms. Kempny and colleagues point to the latter approach as a driver of higher mortality among ACHD patients who miss clinic visits.<sup>4</sup> A second explanation is that clinic nonattendance is a marker for poor self-care, such as diet and medication nonadherence.<sup>31,32</sup> In patients treated for heart failure, good adherence to self-care has been associated with decreased resource utilization and improved health status, while poor self-care was found to be predictive of increased emergency department visits and hospitalizations.<sup>32</sup> Missed appointments may indicate to a clinician that a patient needs further education and assistance with self-care.

Despite similar frequencies and reasons for ED visits and hospital admissions, we did not observe a significant relationship between clinic nonattendance and hospitalizations. Given that nearly 40% of hospitalizations originated from the ED, the relationship between nonattendance and hospitalizations likely bears similarities to the relationship between nonattendance and ED visits. Accordingly, we found that the ratio of cardiac to noncardiac visit reasons was roughly the same for ED visits and hospitalizations. We believe that the borderline results of our hospitalization survival analysis indicate a tendency that may be revealed by a larger sample. To assess whether admissions for pregnancy had an impact on outcomes, we repeated our logistic regression and survival analyses after excluding admissions for delivery as this is considered an unavoidable admission. Excluding these admissions yielded no change in outcomes (all P values > 0.05). Other studies that associate nonattendance with subsequent acute care utilization do not differentiate between mechanisms for ED visits and hospitalizations, but generally attribute both outcomes to poor continuity of care.9,33,34

We have shown that ACHD clinic nonattendance is a marker of populations with barriers to care. Following this study, we made efforts to decrease no-show in our practice through implementing a system of contacting patients after their missed appointments. The next step from a quality improvement perspective is to examine the impact of this intervention on the rate of nonattendance in our clinic and to examine targeted interventions such as text messaging to patients with a history of no-show to prevent recurrence. Clinicians are encouraged to engage and educate their patients on the importance of regular assessment and adherence to care, but further attempts to assess barriers to care specific to the patient are warranted. Ultimately, the first steps toward self-care in ACHD patients are transition readiness assessment, education, and engagement during youth. By instilling early practices of self-care, clinicians may have a long-lasting impact on future outcomes.

## 4.1 | Limitations

Our findings have several limitations. The 3-year follow-up limits our ability to detect differences in outcomes, particularly death. Future studies performed with longer follow-up and larger samples may yield more conclusive findings for hospitalizations and death. As a single-center retrospective study, our results may not be generalizable to the ACHD population as a whole. Our sample is predominately white, insured, and of higher income. Nonetheless, our investigation is a novel inquiry into clinic attendance at an inner city tertiary care ACHD center in the United States. Our data did not capture ED visits and hospitalizations that occurred outside of the University of Pennsylvania Health System. However, by manually assessing medical records rather than utilizing administrative databases, we have provided granular data on ED visits and hospital admissions in ACHD patients that is largely independent of errors in coding.

## 5 | CONCLUSIONS

Our findings lend important support for routine follow-up at specialized ACHD clinics. We provide new evidence that nonattendance of ACHD outpatient clinic appointments is associated with multiple ED visits. Furthermore, we have identified characteristics which may help clinicians target and reduce nonattendance. With the medical advances and continued growth of the ACHD population, it is more important than ever to direct resources toward supporting a proactive approach to self-care.

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#### CONFLICT OF INTEREST

The authors declared that they have no conflicts of interest with the contents of this article.

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