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Cardiology Care and Loss to Follow-Up Among Adults With Congenital Heart Defects in CH STRONG

Jennifer G. Andrews, PhD^{a,*}, Danielle Strah, MD^a, Karrie F. Downing, MPH^b, Matthew C. Kern, MD^c, Matthew E. Oster, MD, MPH^{b,d}, Michael D. Seckeler, MD, MSc^a, Anthony Goudie, PhD^e, Wendy N. Nembhard, PhD, MPH^e, Sherry L. Farr, PhD^b, Scott E. Klewer, MD^a

^aDepartment of Pediatrics, University of Arizona, Tucson, Arizona

^bNational Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia

^cSchool of Medicine, University of Arizona, Tucson, Arizona

^dChildren's Healthcare of Atlanta, Emory University School of Medicine, Atlanta, Georgia

^eDepartment of Epidemiology, University of Arkansas for Medical Sciences, Little Rock, Arkansas. Manuscript received November 29, 2022; revised manuscript received and accepted April 3, 2023.

Abstract

Many of the estimated 1.4 million adults with congenital heart defects (CHDs) in the United States are lost to follow-up (LTF) despite recommendations for ongoing cardiology care. Using 2016 to 2019 CH STRONG (Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG) data, we describe cardiac care among community-based adults with CHD, born in 1980 to 1997, identified through state birth defects registries. Our estimates of LTF were standardized to the CH STRONG eligible population and likely more generalizable to adults with CHD than clinic-based data. Half of our sample were LTF and more than 45% had not received cardiology care in over 5 years. Of those who received care, only 1 in 3 saw an adult CHD physician at their last encounter. Not knowing they needed to see a cardiologist, being told they no longer needed cardiology care, and feeling “well” were the top reasons for LTF, and only half of respondents report doctors discussing the need for cardiac follow-up.

Many of the estimated 1.4 million adults with congenital heart defects (CHD) in the United States are lost to follow-up (LTF), despite recommendations for ongoing cardiology care.¹ Remaining in cardiac care is associated with CHD complexity, higher education, and receiving care from adult CHD providers,² but data are limited to patients in adult congenital heart disease (ACHD) care centers or administrative databases that exclude those who are currently out of care or receiving care from noncongenital cardiologists. Therefore, we estimate the community receipt of recommended cardiac care and LTF.

*Corresponding author: Tel: 520-626-6816; fax: 520-626-8056. Jandrews@peds.arizona.edu (J.G. Andrews).

Declaration of Competing Interest

The authors have no conflicts of interest to declare.

Methods

Using the 2016 to 2019 CH STRONG (Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG) data, we describe cardiac care among community-based adults with CHD, born in 1980 to 1997, identified through state birth defects registries.³ Severe CHD was classified using diagnostic codes selected by cardiologists.³ LTF was calculated using 2018 guidelines by defect.⁴ The most severe diagnosis per participant was mapped to recommendations under New York Heart Association classification A. The descriptive statistics included chi-square and analysis of variance analyses. To reduce potential for response bias, the LTF estimate was standardized to site and year of birth, gender assigned at birth, maternal race/ethnicity, and CHD severity across all CH STRONG eligible respondents. The prevalence ratio were estimated with Poisson regression, and standard errors were calculated using conditional standardization and the delta method on 9,312 eligible individuals (including non-respondents). All analyses were conducted in R (<https://www.R-project.org/>) and SAS (SAS Institute Inc., Cary, North Carolina). A $p > 0.05$ was considered significant.

Results

Of 1,656 respondents, 3.4% did not have a CHD represented in the guidelines⁵ and 1.4% did not report their last cardiology visit, leaving 1,576 individuals for analysis. Participant characteristics are described in Table 1. After standardization, 45.6% last saw a cardiologist over 5 years ago (30.4%) or never (15.2%), and 50.4% were LTF at time of survey. No association was seen between the type of cardiologist visited most recently and LTF (Figure 1); however, there was a negative correlation between age and care from a pediatric cardiologist ($p < 0.01$; Figure 1).

Having severe CHD, concerns about the ability to have children and a provider who discussed the need for lifelong cardiac care were associated with lower risk of LTF. Among men, hospital admission in the past 12 months was associated with reduced LTF; among women, severe CHD and concern with ability to have children were associated with reduced LTF (Table 1).

The top reasons for not seeing cardiology care in the past 5 years were not knowing they needed to see a cardiologist (48%) and feeling well (43%; Figure 1). In addition, 24% with severe and 39% with nonsevere CHD reported that a doctor told them they no longer needed to see a cardiologist and 18% and 6%, respectively, reported insurance issues as barriers to seeing a cardiologist (both $p < 0.05$).

Conclusions

The recent estimates of LTF, based on single centers and 1 nonclinic cohort, are 26% internationally (Canada, United States, Belgium, Sweden) and 34% in the United States.⁵ Our estimates of LTF were standardized to the CH STRONG eligible population and likely more generalizable to adults with CHD than clinic-based data. Half of our sample were LTF, according to recommendations for their specific CHD, and more than 45% had not received

cardiology care in over 5 years. Of those who received care, only 1 in 3 saw an ACHD physician at their last encounter.

Individuals with CHD commonly leave cardiac care during adolescence and, for those who return, the median gap in CHD care is 10 years.⁶ The receipt of cardiac care in the previous 5 years was highest for the youngest (aged 19 years) and oldest (aged 38 years) participants. We observed an increasing trend in ACHD care with age, but an equal or greater percentage of those aged 35–38 years received their care from an adult cardiologist without CHD training, despite the guidelines specifying transition to an ACHD cardiologist. Within the 3 CH STRONG sites, there are between 1 – 3 million patients per ACHD physician, and this shortage of board-certified ACHD physicians will increase as the ACHD population in the United States continues to grow.⁷

CHD severity is a predictor for staying in cardiac care and people with less complex lesions are at increased risk for LTF, mirroring our findings.^{1,5} Biologic gender was not associated with LTF in our analyses; however, it modified other associations with LTF. Studies found mixed results for socioeconomic associations with LTF, and we did not find associations between race/ethnicity, delay of care because of cost, or employment and LTF.^{2,8,9} Associations between type of cardiologist last seen and LTF are mixed;^{2,8,9} we did not find an association. A study identified the lack of or change in insurance contributing to LTF,¹ similar to our findings, while another did not.²

The strengths of this manuscript lie in the community-based CH STRONG cohort. Clinic samples are likely skewed toward individuals who have transitioned and may underrepresent those LTF early in adulthood. The limitations include categorical responses for last cardiology visit not always aligning with the guidelines. Our data are based on self- or proxy report and prone to recall issues. Potential for response bias is present so our LTF estimate was standardized to account for this.

Only half of respondents report doctors discussing the need for cardiac follow-up. Not knowing they needed to see a cardiologist, being told they no longer needed cardiology care, and feeling “well” were the top reasons for LTF. Patients with ACHD discussing the need for cardiology care with physicians were 3 times more likely to stay in care.¹⁰ Starting in childhood, cardiologists and primary care providers may increase awareness and prevent LTF by discussing need for cardiac follow-up with their patients.

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Abbreviations:

lifelong care	lifelong care
Fontan	Fontan
LTF	Lost to follow-up

CHD	Congenital heart defects
ACHD	adult congenital heart disease
TOF	Tetralogy of Fallot

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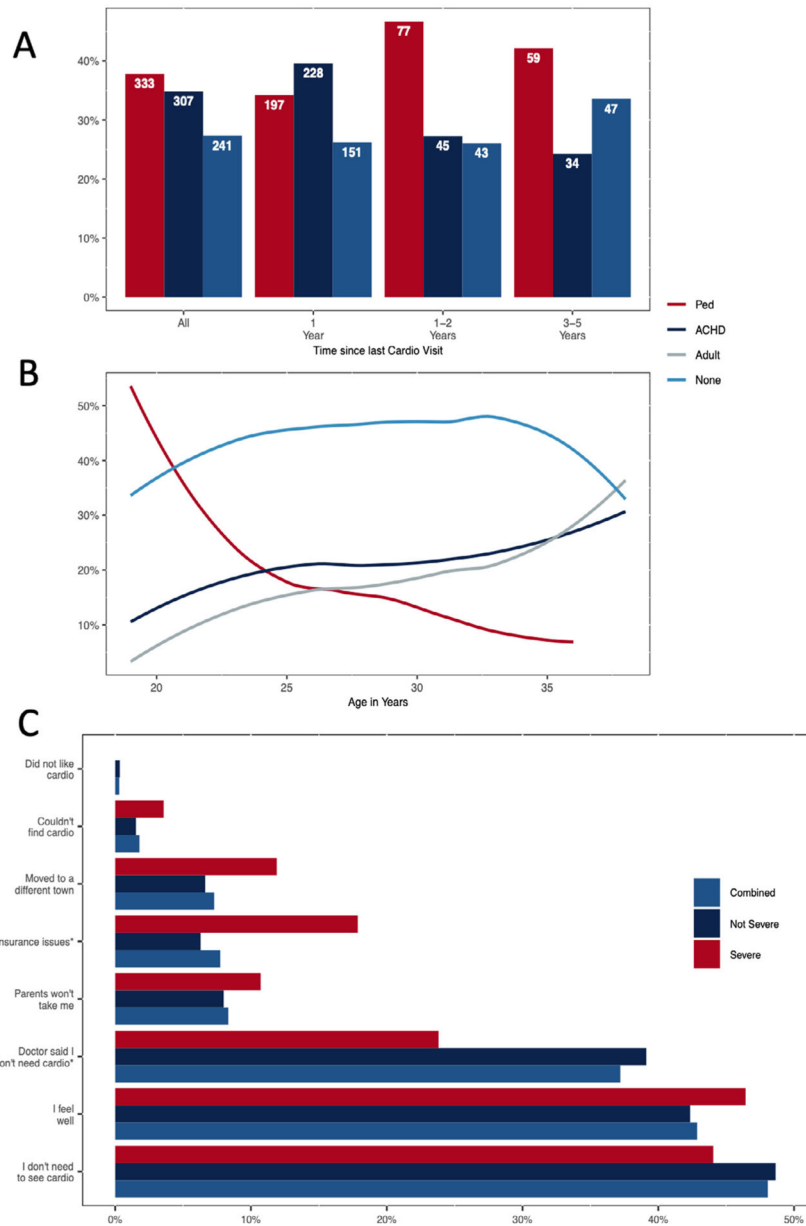


Figure 1. Data shown represent (A) time since last cardiology visit and (B) age at survey by type of cardiologist last seen for the 881 young adults with CHD who saw a cardiologist in past 5 years and (C) reasons why the remaining 659 young adults did not see a cardiologist by CHD severity, CH STRONG, 2016 to 2019. *p <0.05.

Demographic characteristics and factors associated with LTF among young adults with congenital heart defects, CH STRONG 2016–2019

Table 1

	All cases N=1576	Yes n=758 (%*)	Lost to cardiac follow-up		
			Bivariate	Multivariable	PR (95% CI)
			Male	Female	
Severe CHD					
No	1032	611(60)			
Yes	544	147 (27)	0.5 (0.4 – 0.5)	0.7 (0.6 – 0.9)	0.82 (0.6 – 1.1)
Race/ethnicity					
Non-Hispanic White	1080	507 (53)			
Non-Hispanic Black	224	113(54)	1.1 (0.9 – 1.3)	1.1 (0.9 – 1.3)	1.1 (0.7 – 1.5)
Hispanic	164	68 (52)	0.9 (0.7 – 1.1)	1.0 (0.7 – 1.2)	0.9 (0.6 – 1.4)
Non-Hispanic other	94	62 (73)	1.4 (1.1 – 1.8)	1.3 (1.0 – 1.7)	1.6 (1.1 – 2.3)
Worked at least part-time past 12 months					
No	400	168 (46)			
Yes	1162	580 (52)	1.2 (1.0 – 1.4)	1.1 (0.9 – 1.4)	1.1 (0.8 – 1.5)
Denied disability					
No	1249	641 (52)			
Yes	201	63 (34)	0.6 (0.5 – 0.8)	0.9 (0.7 – 1.2)	0.8 (0.5 – 1.2)
Cardiac comorbidity					
No	1172	596 (54)			
Yes	404	162 (43)	0.79 (0.7 – 0.9)	0.9 (0.8 – 1.1)	0.8 (0.6 – 1.1)
Used emergency room past 12 months					
No	1076	551 (53)			
Yes	499	207 (44)	0.8 (0.7 – 0.9)	0.9 (0.8 – 1.1)	0.9 (0.7 – 1.2)
Admitted to hospital past 12 months					
No	1374	693 (53)			
Yes	201	65 (36)	0.6 (0.5 – 0.8)	0.8 (0.6 – 1.0)	0.6 (0.2 – 0.9)
Type of insurance					
Private	886	413 (48)			
Public	442	190 (46)	0.9 (0.8 – 1.1)	1.0 (0.9 – 1.3)	1.1 (0.8 – 1.4)

	All cases N=1576	Yes n=758 (%)*	Lost to cardiac follow-up			
			Bivariate	Multivariable	Male	Female
Other	73	35 (52)	1.0 (0.7 – 1.4)	1.1 (0.8 – 1.6)	1.3 (0.7 – 2.4)	1.1 (0.6 – 1.7)
None	156	105 (66)	1.4 (1.2 – 1.8)	1.3 (1.0 – 1.7)	1.3 (0.9 – 2.0)	1.3 (0.9 – 1.8)
Concern with health in general						
Not at all – not very	745	411 (56)				
Somewhat – very	793	332 (46)	0.8 (0.7 – 0.9)	1.1 (0.9 – 1.4)	1.1 (0.8 – 1.5)	1.18 (0.9 – 1.56)
Concern with overall heart health						
Not at all – not very	793 (52)	467 (59)				
Somewhat – very	740 (48)	277 (41)	0.6 (0.6 – 0.7)	0.8 (0.7 – 1.0)	0.9 (0.6 – 1.2)	0.8 (0.6 – 1.1)
Concern with ability to have children						
Not at all – not very	1108 (73)	578 (54)				
Somewhat – very	421 (28)	162 (45)	0.7 (0.6 – 0.9)	0.8 (0.7 – 0.9)	1.0 (0.7 – 1.4)	0.8 (0.6 – 0.9)
Healthcare provider discussed need for follow-up						
Yes	814 (52)	172 (24)				
No	744 (48)	582 (74)	3.7 (3.1 – 4.4)	3.1 (2.5 – 3.8)	2.8 (2.1 – 3.7)	3.3 (2.5 – 4.5)

* Values represent percentages after sample standardization to site, birthyear, gender, maternal race/ethnicity, and CHD severity across all respondents and nonrespondents.

Variables tested but not contributory in bivariate analyses: Sex at birth; age; comorbid noncardiac birth defect; high school completion; delayed care because of cost; Unable to pay for care past 12 months; additional noncardiac comorbidity; changed provider because of insurance past 12 months.

CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being; CHD = congenital heart defect; CI = confidence interval; LTF = lost to cardiac care follow-up; PR = prevalence ratio.