

# Mental Health Disorders in Children With Congenital Heart Disease

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abstract

**BACKGROUND:** Data on anxiety, depression, and attention-deficit/hyperactivity disorder (ADHD) are lacking for youth with congenital heart disease (CHD), particularly those with simple CHD. This study aims to characterize these disorders in youth with CHD compared to those without CHD.

**METHODS:** A comparative cross-sectional study was conducted by using the electronic medical records of a large tertiary care hospital between 2011 and 2016. Inclusion criteria were youth aged 4 to 17 years with >1 hospitalization or emergency department visits. Exclusion criteria were patients with arrhythmias or treatment with clonidine and/or benzodiazepines. The primary predictor variable was CHD type: simple, complex nonsingle ventricle, and complex single ventricle. The primary outcome variable was a diagnosis and/or medication for anxiety and/or depression or ADHD. Data were analyzed by using logistic regression (Stata v15; Stata Corp, College Station, TX).

**RESULTS:** We identified 118 785 patients, 1164 with CHD. Overall, 18.2% ( $n = 212$ ) of patients with CHD had a diagnosis or medication for anxiety or depression, compared with 5.2% ( $n = 6088$ ) of those without CHD. All youth with CHD had significantly higher odds of anxiety and/or depression or ADHD. Children aged 4 to 9 years with simple CHD had ~5 times higher odds (odds ratio: 5.23; 95% confidence interval: 3.87–7.07) and those with complex single ventricle CHD had ~7 times higher odds (odds ratio: 7.46; 95% confidence interval: 3.70–15.07) of diagnosis or treatment for anxiety and/or depression. Minority and uninsured youth were significantly less likely to be diagnosed or treated for anxiety and/or depression or ADHD, regardless of disease severity.

**CONCLUSIONS:** Youth with CHD of all severities have significantly higher odds of anxiety and/or depression and ADHD compared to those without CHD. Screening for these conditions should be considered in all patients with CHD.



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**WHAT'S KNOWN ON THIS SUBJECT:** Data have revealed adolescents with complex congenital heart disease have higher burdens of mental health disorders compared with the general population. Data on anxiety, depression, and attention-deficit/hyperactivity disorder are lacking for children and in youth with simple cardiac defects.

**WHAT THIS STUDY ADDS:** Youth with congenital heart disease of all severities have significantly higher odds of anxiety/depression and attention-deficit/hyperactivity disorder compared with their peers. Screening should be considered for all congenital heart disease patients and possibly for children with other chronic illnesses.

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Congenital heart disease (CHD) is the most common birth defect, affecting ~1% of all live births.<sup>1</sup> The spectrum of CHD is wide, ranging from simple (not requiring immediate or possibly any surgical intervention) to severe or complex (typically defined as CHD requiring surgical intervention within the first month to year of life).<sup>2</sup> Although overall mortality has improved, most notably in those with complex CHD, many surgical and medical procedures are palliative, and these patients often require multiple interventions throughout their lifetime.<sup>3</sup> Increased CHD survival is now resulting in a continually growing population of adolescents and adults with CHD; this has drawn more attention to the noncardiac comorbidities, including overall mental health, of patients with CHD.<sup>4</sup>

There are multiple psychological theories that can potentially explain some of the mental health disorders seen in patients with CHD, such as stressful life events and sociocultural impacts (eg, parenting style).<sup>5-7</sup> Cognitive models, including learned helplessness and negative information processing, may also contribute to the mental health of children with CHD, who often spend significant amounts of time in the hospital and undergo cardiac procedures and surgeries.<sup>5,6</sup> The presence of underlying genetic syndromes, parental mental health disorders, cardiopulmonary bypass, prematurity, and prolonged hospitalizations are factors that increase the risk of neurodevelopmental disabilities (NDDs) and likely contribute to anxiety, depression, and attention-deficit/hyperactivity disorder (ADHD) in adolescents and adults with complex CHD.<sup>8-13</sup> With recent data, it is estimated that 50% to 75% of children with complex CHD are affected by NDDs and reduced quality of life.<sup>8,12,13</sup> Given that the aforementioned models extend into childhood, it is notable that there is

a paucity of literature examining the treatment of these disorders in young patients and in those with simple CHD. Thus, the purpose with this study was to determine the prevalence of anxiety, depression, and ADHD in children with CHD and compare them with youth without CHD. We hypothesized that the prevalence of these conditions would likely be higher in youth with CHD compared with patients without CHD and that children with complex CHD would have higher rates of anxiety, depression, and ADHD compared with those with simple CHD.

## METHODS

The research was approved by multi-institutional review boards. Inpatient and emergency department (ED) records from Texas Children's Hospital were queried from 2011 to 2016 (medication data not available for outpatient encounters). Inclusion criteria were youth 4 to 17 years with at least 1 electronic medical record of being hospitalized or seen in the ED and at least 1 hospital medication file; a cutoff age of 4 years was used because diagnoses of anxiety, depression, and ADHD can reliably be made at this age.<sup>14</sup> Individual patients were treated as one record, regardless of their number of encounters. Exclusion criteria included patients >18 years, those with any arrhythmia, and treatment with clonidine or benzodiazepines (often used for sedation).

The primary outcome variable was diagnosis or treatment with a medication for anxiety and/or depression, ADHD, or both (*International Classification of Diseases, Ninth Revision* [ICD-9] codes/list of medications, Supplemental Table 6). Given that the same medications are used to treat both conditions, the diagnoses of anxiety and depression were collapsed (the absolute reason for medication use could not be

determined with available data). The primary predictor variable was whether the child had a diagnosis of CHD, which was defined by using the physiologic adult congenital heart disease (ACHD) criteria<sup>3</sup> of complexity as simple, complex nonsingle ventricle (NSV), and complex single ventricle (SV) (CHD diagnoses, Supplemental Table 7). Sociodemographics served as secondary predictor variables. Sex was characterized as a dichotomous variable, with female as the referent. Age was assessed as a continuous measure for the initial regression model. For subsequent models, patients were grouped by age into categories of preadolescent (4–9 years), early adolescent (10–13 years), and late adolescent (14–17 years). Race or ethnicity was a categorical measure representing the parent-reported race or ethnicity of the child, with non-Hispanic white as the referent. Insurance type was a categorical measure and indicated the type of insurance held by the child at the time of the visit.

The statistical significance of each predictor variable was defined as a *P* value <.05 and an odds ratio >1 or <1. The first logistic regression model assessed all patients, with age as a continuous variable. Two subsequent models were performed stratified by age groups; because of the small number of early and late adolescent patients with complex SV CHD, this subanalysis could not be completed. Data were analyzed by equity of proportions and logistic regression using Stata v15 (Stata Corp, College Station, TX).

## RESULTS

### Patient Characteristics

We identified 118 785 unique patients, 1164 (~1%) of whom had CHD. Patient demographics are shown in Table 1. The majority of patients with CHD had simple (47.7%) or complex NSV (46.9%)

**TABLE 1** Patient Population

	Patients With CHD	Patients Without CHD
All Patients 4–17 y ( <i>N</i> = 118 785)	1164	117 621
Age, y, <i>n</i> (%)		
4–9	710 (61.0)	63 015 (53.6)
10–13	244 (21.0)	29 461 (25.1)
14–17	210 (18.0)	25 145 (21.4)
Male, <i>n</i> (%)	661 (56.8)	61 063 (52.0)
Race and ethnicity, <i>n</i> (%)		
NH white	456 (39.2)	29 848 (25.4)
NH Black	170 (14.6)	23 247 (19.8)
Hispanic	451 (38.8)	57 592 (49.0)
Asian American or other	53 (4.6)	4208 (3.6)
Race missing	34 (2.9)	2726 (2.3)
Insurance, <i>n</i> (%)		
Public	571 (49.0)	63 781 (54.2)
Private	564 (48.5)	45 418 (38.6)
Self-pay or international	29 (2.5)	8422 (7.2)
CHD complexity, <i>n</i> (%)		
Simple	555 (47.7)	N/A
Complex, NSV	546 (46.9)	N/A
Complex, SV	63 (5.4)	N/A

NH, non-Hispanic; N/A, not applicable.

lesions. Compared with patients without CHD, those with CHD had more 4- to 9-year-olds (61.0% vs 53.6%), were more male-predominant (56.8% vs 52.0%), had a higher percentage of non-Hispanic white individuals (38.8% vs 25.4%), and were more likely to be privately insured (48.5% vs 38.6%). We adjusted for all of these factors in our statistical multivariate models.

### Prevalence of Anxiety and/or Depression and ADHD

Table 2 details patients with a diagnosis or medication for anxiety and/or depression or ADHD, both by age and presence or absence of CHD diagnosis. Overall, children with CHD had a significantly higher prevalence

of anxiety and/or depression (18.2% vs 5.2%,  $P < .05$ ) and ADHD (5.1% vs 2.1%,  $P < .05$ ). This held true when children were stratified by age (Table 2).

### Logistic Regression Models

In the first logistic regression model, all patients were analyzed with age as a continuous variable. The odds of having a diagnosis or medication for anxiety and/or depression or ADHD increased as children aged (Table 3). Compared with children without CHD, those with CHD had ~4 to 5 times the odds of diagnosis or treatment of anxiety and/or depression and ~1.6 to 2.7 times the odds of ADHD (Table 3). Non-Hispanic Black, Hispanic, and Asian American or

other race children with CHD were 47%, 52%, and 33% less likely to be diagnosed or treated for anxiety and/or depression, respectively (Table 3). For ADHD, non-Hispanic Black, Hispanic, and Asian American or other race children with CHD were 45%, 78%, and 86% less likely to be diagnosed or treated for this condition, respectively (Table 3). These odds held true even when controlling for insurance type.

For the second and third models, age was a categorical variable for anxiety and/or depression (Table 4) and ADHD (Table 5). All patients, with simple or complex CHD, had higher odds of being diagnosed or treated for anxiety and/or depression (Table 4) and/or ADHD (Table 5), compared with their peers without CHD. These odds were most pronounced for anxiety and/or depression in the preadolescent group, and in particular, for those with SV CHD diagnoses. Those with public insurance generally had higher odds of being diagnosed or treated for ADHD, compared with those with private insurance or self-pay (Table 5).

### DISCUSSION

The results of our study demonstrate that patients with CHD, regardless of age or disease severity, appear to have a significantly higher burden of anxiety and/or depression and ADHD when compared with peers without CHD. Our study adds significantly to

**TABLE 2** Prevalence of Anxiety, Depression, ADHD, by Age and CHD Status

	Anxiety and/or Depression			ADHD		
	All Patients with CHD ( <i>N</i> = 1164), Anxiety and/or Depression <i>n</i> (%)	All Other Patients ( <i>N</i> = 117 621), Anxiety and/or Depression <i>n</i> (%)	<i>P</i>	All Patients with CHD ( <i>N</i> = 1164), ADHD <i>n</i> (%)	All Other Patients ( <i>N</i> = 117 621), ADHD <i>n</i> (%)	<i>P</i>
Age 4–9	117 (16.5)	1949 (3.1)	<.05	22 (3.1)	868 (1.4)	<.05
Age 10–13	46 (18.9)	1863 (6.4)	<.05	20 (8.2)	855 (2.9)	<.05
Age 14–17	49 (23.3)	2276 (9.2)	<.05	17 (8.1)	676 (2.7)	<.05
Total	212 (18.2)	6088 (5.2)	<.05	59 (5.1)	2399 (2.1)	<.05

*P* values denote tests of equality of proportions for anxiety and/or depression and ADHD, within age groups, between patients with CHD and all other patients.

**TABLE 3** Logistic Regressions, All Hospitalized and ED Patients <18 Years

	Anxiety and/or Depression			ADHD			Anxiety and/or Depression and ADHD		
	Odds Ratio	95% CI	P	Odds Ratio	95% CI	P	Odds Ratio	95% CI	P
Age	1.13	1.12–1.13	<.05	1.09	1.08–1.11	<.05	1.11	1.09–1.13	<.05
Diagnosis (reference: non-CHD)									
Simple CHD	3.97	3.15–5.00	<.05	2.65	1.83–3.83	<.05	4.45	2.54–7.83	<.05
Complex NSV CHD	4.04	3.22–5.06	<.05	1.95	1.28–2.97	<.05	3.04	1.55–5.93	<.05
Complex SV CHD	5.24	2.73–10.06	<.05	1.59	0.38–6.66	.53	N/A	N/A	N/A
Race or ethnicity (reference: NH white)									
NH Black	0.53	0.49–0.57	<.05	0.55	0.49–0.61	<.05	0.46	0.36–0.57	<.05
Hispanic	0.48	0.45–0.52	<.05	0.22	0.20–0.24	<.05	0.20	0.16–0.26	<.05
Asian American or other	0.67	0.58–0.77	<.05	0.14	0.10–0.21	<.05	0.17	0.08–0.36	<.05
Insurance type (reference: private)									
Public	1.04	0.98–1.10	.24	1.68	1.53–1.84	<.05	1.50	1.24–1.81	<.05
Self-pay	0.47	0.41–0.55	<.05	0.37	0.28–0.51	<.05	0.21	0.09–0.47	<.05
Sex (reference: female)									
Male	1.01	0.96–1.06	.69	2.11	1.94–2.30	<.05	1.87	1.57–2.23	<.05

NH, non-Hispanic; N/A, not applicable.

the body of mental health and CHD literature, because there are no studies that include an assessment of anxiety and/or depression and ADHD in young children or those with simple CHD. Our findings are consistent with current data in adolescents with complex CHD, which reveal an increase in anxiety symptoms,<sup>15</sup> as well as studies in the literature suggesting an increased prevalence of anxiety, depression, and ADHD in adolescents with CHD.<sup>15–18</sup> These findings also correlate with the limited data in children with other chronic illnesses, such as asthma or sickle cell disease, which suggest an increase in mental health disorders compared with their peers.<sup>19,20</sup>

Our study is unique in that there are few published studies in which researchers use diagnosis codes and medication data instead of self-report surveys to evaluate for anxiety, depression, and ADHD in the CHD population <18 years of age. Given that most anxiety and/or depression and ADHD diagnoses are made in the outpatient setting, we feel that our prevalence data are likely generalizable beyond the inpatient or ED setting. Although choosing the inpatient or ED setting may raise the question of a selection bias toward sicker patients, current outpatient data are congruent and reveal a similar trend in NDDs and mental health disorders.<sup>15,21–23</sup>

### Anxiety and Depression

Existing literature does not currently examine anxiety or depression in patients with CHD aged <10 years. This study demonstrates that young children, regardless of CHD complexity, have a higher odds of diagnosis or treatment of anxiety and/or depression. Thus, limiting screening for anxiety and/or depression to adolescents with SV CHD or ACHD patients may result in the underdiagnosis in children and those with simple CHD.

The reported national prevalence of anxiety and depression in the general population of 2- to 11-year-olds is roughly 3% and 7%, respectively.<sup>24</sup>

**TABLE 4** Logistic Regressions, Stratified by Age, Anxiety and/or Depression

	Youth Aged 4–9 y			Youth Aged 10–13 y			Youth Aged 14–17 y		
	Odds Ratio	95% CI	P	Odds Ratio	95% CI	P	Odds Ratio	95% CI	P
Diagnosis (reference: non-CHD)									
Simple CHD	5.23	3.87–7.07	<.05	2.78	1.70–4.55	<.05	2.84	1.75–4.61	<.05
Complex NSV CHD	5.82	4.29–7.89	<.05	3.24	2.06–5.10	<.05	2.33	1.46–3.70	<.05
Complex SV CHD	7.46	3.70–15.07	<.05	N/A	N/A	N/A	N/A	N/A	N/A
Race or ethnicity (reference: NH white)									
NH Black	0.59	0.52–0.68	<.05	0.55	0.48–0.63	<.05	0.47	0.41–0.53	<.05
Hispanic	0.48	0.43–0.54	<.05	0.48	0.43–0.55	<.05	0.47	0.43–0.53	<.05
Asian American or other	0.54	0.42–0.69	<.05	0.61	0.47–0.80	<.05	0.97	0.76–1.23	.80
Insurance type (reference: Private)									
Public	1.25	1.12–1.39	<.05	0.98	0.87–1.09	.65	0.91	0.82–1.00	.05
Self-pay	0.54	0.41–0.70	<.05	0.47	0.36–0.61	<.05	0.44	0.35–0.56	<.05
Sex (reference: female)									
Male	1.05	0.96–1.15	.30	0.80	0.73–0.88	<.05	1.16	1.07–1.27	<.05

NH, non-Hispanic; N/A, not applicable.

**TABLE 5** Logistic Regressions, Stratified by Age, ADHD

	Youth Aged 4–9 y			Youth Aged 10–13 y			Youth Aged 14–17 y		
	Odds Ratio	95% CI	P	Odds Ratio	95% CI	P	Odds Ratio	95% CI	P
Diagnosis (reference: non-CHD)									
Simple CHD	2.16	1.20–3.89	<.05	3.71	2.07–6.64	<.05	2.08	0.90–4.83	.09
Complex NSV CHD	2.02	1.07–3.84	<.05	1.45	0.63–3.35	.38	2.38	1.14–4.96	<.05
Complex SV CHD	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Race or ethnicity (reference: NH white)									
NH Black	0.60	0.50–0.71	<.05	0.52	0.43–0.62	<.05	0.53	0.43–0.65	<.05
Hispanic	0.20	0.17–0.24	<.05	0.22	0.18–0.26	<.05	0.25	0.20–0.30	<.05
Asian American or other	0.14	0.08–0.25	<.05	0.13	0.06–0.26	<.05	0.17	0.07–0.38	<.05
Insurance type (reference: Private)									
Public	1.85	1.58–2.17	<.05	1.68	1.43–1.97	<.05	1.47	1.23–1.75	<.05
Self-pay	0.34	0.19–0.59	<.05	0.37	0.22–0.61	<.05	0.42	0.25–0.70	<.05
Sex (reference: female)									
Male	2.38	2.04–2.76	<.05	1.82	1.57–2.10	<.05	2.00	1.71–2.34	<.05

NH, non-Hispanic; N/A, not applicable.

Our study reveals a significantly higher prevalence, with ~16% of patients with CHD aged 4 to 9 years having a diagnosis or medication for anxiety and/or depression. The etiology behind this increased odds of anxiety and/or depression in young patients with simple CHD is likely multifactorial. As previously mentioned, prematurity and underlying genetic syndromes in these patients (eg, trisomy 21, Turner syndrome, Marfan syndrome, Noonan syndrome) are commonly associated with ADHD, oppositional disorders, and anxiety or depression,<sup>25–28</sup> and may inherently increase their risk of mental health disorders; <1% of patients in our data set were coded for one of the aforementioned genetic diagnoses. Additionally, the impact of increased parental stress, coping, and anxiety has been well described in parents of children with CHD.<sup>29,30</sup> There are multiple theoretical models (eg, double ABCX, Thompson stress and coping model),<sup>31–33</sup> as well as a model unique to infants with CHD,<sup>34,35</sup> in support of this hypothesis. Obesity is a common acquired condition that is prevalent in the population of CHD patients and is correlated with higher rates of ADHD, depression, and conduct disorder diagnoses.<sup>36,37</sup> Furthermore, the significant burden of noncardiac comorbidities (eg, endocrine and metabolic, gastrointestinal,

gynecologic disorders) in the ACHD population likely contributes to an increase in mental health disorders as well; these may also affect pediatric populations with CHD who are seeing similar comorbidities at younger ages in the current era.<sup>37–39</sup> Finally, there are data to suggest that adolescents and adults with any type of CHD are at increased risk for psychological comorbidities, including posttraumatic stress disorder, which may also occur in younger children.<sup>23,38,40</sup>

Adolescent data in patients with CHD have previously revealed that those with a greater number of heart operations, lower systemic saturation, and complex SV disease were at significantly increased risk for having psychiatric diagnoses and behavioral disorders<sup>15–17,41</sup> and had higher rates of mental health disorders compared with their peers.<sup>15–17,21,42</sup> Our data reveal that adolescents with any type of CHD have a higher prevalence of anxiety and/or depression than their peers without CHD (19%–23% vs 6%–9%), but that the odds were less pronounced between those with and without CHD as they aged. One possible explanation behind this smaller difference between the groups is the higher national prevalence of anxiety and/or depression in adolescent populations (6%–11%<sup>24</sup> for 12–17-year-olds),

compared with preadolescent patients, regardless of chronic disease condition. One novel study finding is that adolescents with simple CHD have >2 times higher odds of anxiety and/or depression compared with peers without CHD. This group may contribute to studies revealing high rates of anxiety and depression in ACHD patients, with up to 50% meeting criteria for a mood or anxiety disorder.<sup>9,43,44</sup>

Our data reveal a lower odds of diagnosis or treatment of anxiety and/or depression for non-Hispanic Black, Hispanic, and Asian American or other race patients, as compared with their non-Hispanic white peers regardless of age, despite prevalence of these conditions being similar in the general population.<sup>45</sup> Potential reasons for this include disparities in access to and quality of mental health services for anxiety and/or depression for minority children, as compared with non-Latino white peers.<sup>46</sup> Other studies have shown that cultural differences or stigma surrounding anxiety and depression and access to insurance that covers mental health services exist among these racial and ethnic groups, resulting in a lower likelihood of seeking care.<sup>46,47</sup>

Our data support the notion that the population of patients with CHD, regardless of disease severity, would

likely benefit from mental health screening and evidence-based therapy earlier in childhood. Data regarding the treatment of children with CHD remain limited. Two efficacious interventions for youth with CHD have been described, one focusing on disease management strategies and the other on relaxation and stress management.<sup>48–50</sup> Parent management training and cognitive behavioral therapy (CBT) may effectively treat anxiety and depressive symptoms.<sup>51–53</sup> There are emerging data to support CBT with the addition of pharmacotherapy in adults, with promising preliminary results revealing a reduction in both anxiety and depressive symptoms.<sup>54,55</sup> Thus, it may be beneficial to have dedicated mental health providers who specialize in pediatric chronic illnesses working with younger CHD patients to provide CBT and pharmacotherapy together. Finally, there are limited data to suggest a possible role for e-health interventions to improve access to therapy for mental health disorders.<sup>56</sup>

## ADHD

The overall national prevalence of children with ADHD is roughly 9% in children aged 3 to 17 years.<sup>57</sup> Our data reveal a prevalence of ADHD diagnosis and treatment in youth with CHD aged 4 to 17 years of 5.1%, whereas the non-CHD population had a lower prevalence of ADHD of 2.1%. A potential explanation for this lower overall prevalence in patients without CHD is the current data focus on patients in Houston, Texas, where there is a lower prevalence of ADHD medication prescription than the national average.<sup>58</sup>

Previous studies have shown that 29% of children aged 7 to 15 years undergoing any open-heart surgery <1 year screened positive for symptoms of ADHD.<sup>59</sup> Similarly, in early school-aged children (5–10 years) with complex CHD, data show ~30% of children received high-risk

scores by parents for symptoms of inattention and hyperactivity.<sup>60</sup> Thus, parental scores may potentially overestimate true diagnoses of ADHD. Our results add to the existing body of literature<sup>18,22,59,60</sup> by demonstrating that youth with simple and complex CHD had a significant increase in ADHD compared with healthy peers.

Other studies have shown the odds of ADHD diagnosis in younger children in the general population for African Americans, Hispanics, and children of other races and ethnicities being 69% (95% confidence interval [CI]: 60%–76%), 50% (95% CI: 34%–62%), and 46% (95% CI: 26%–61%) lower, respectively, compared with non-Hispanic white individuals.<sup>61</sup> This may be because of a provider or caregiver's misperception that inattention or poor behavior is part of the child's temperament, as opposed to sequelae of underlying ADHD. A misdiagnosis could result in increased discipline instead of mental health services; studies show that Black children experience disproportionately high rates of school discipline.<sup>62</sup> Parent management training has been shown to be effective in historically underserved populations, including minorities and those of lower socioeconomic status.<sup>63,64</sup>

## Anxiety and Depression, ADHD, and the Impact of Insurance

Our data reveal a decreased odds of diagnosis and/or treatment of anxiety and/or depression and ADHD across all age groups for those patients without insurance, which is not surprising given the cost of mental health treatment. Children covered by consumer-driven and high-deductible private insurance plans have significantly higher out-of-pocket expenditures for mental health services compared with other types of private insurance, which may end in families not being able to afford these services.<sup>65</sup> Fortunately,

Medicaid and Children's Health Insurance Program services require that enrolled children receive a range of medically necessary services, including mental health services.<sup>66</sup> This is of particular importance because untreated mental health disorders in children can lead to costly outcomes, such as school dropout, substance use, and suicide.<sup>67</sup>

## LIMITATIONS

Although, in this study, we demonstrate multiple significant findings in the prevalence of anxiety and/or depression and ADHD in children with varied CHD severity, there are important limitations. Study data were collected at a single center by using diagnosis codes and medication records. Although this provides useful objective data, there are inherent difficulties that come with using ICD-9 diagnosis codes in that they bear the potential for inaccuracy. However, using a medication record helps provide increased accuracy by ensuring that the population was truly being treated for the diagnoses of anxiety and/or depression and ADHD, because these medications are solely used for these conditions. In our electronic medical record data, 98% of patients with anxiety and/or depression and 63% of patients with ADHD were identified using medication records, supporting our decision not to rely solely on ICD-9 codes.

Another limitation is that given the significant overlap in medications used to treat anxiety and depression, patients being treated for each condition separately could not be differentiated. Additionally, patients being treated with benzodiazepines and clonidine were excluded, because these medications are frequently used for sedation purposes, resulting in a potential underestimate of the true number of patients being treated for anxiety. Finally, for our study we used

ED and inpatient data, which raises the possibility of selection bias toward a sicker CHD cohort. It is not uncommon for any patient with CHD, even those with simple CHD, to be hospitalized or seen in the ED at least once over a 6-year period. One study in particular demonstrated that children with CHD accounted for ~3.7% of all hospitalizations in the United States for youth aged 0 to 20 years; ~17% of these CHD hospitalizations had complex CHD, accounting for only 30% of CHD hospitalizations in patients aged 1 to 10 years and 25% of CHD hospitalizations of patients 11 to 20 years.<sup>68</sup> We deliberately chose our population cohort to include patients with both simple and complex CHD, which reduces the likelihood of choosing sicker (more severe) patients with CHD. Adding ED visits also assisted in catching patients who were not hospitalized and increased our catchment of “less sick” patients. Finally, we elected to use an ED and inpatient data set because of the

ability to access medication data to ensure accuracy of diagnosis. Outpatient medical records are often limited to ICD-9 codes for single visit diagnosis and do not encompass all of a patient’s diagnoses or medications.

## CONCLUSIONS

Our study demonstrates significantly increased odds of anxiety and/or depression and ADHD in all youth with CHD, regardless of disease severity. In particular, we provide novel insight into mental health disorders in children aged 4 to 9 years, as well as those with simple CHD. With these findings, we emphasize the importance of potential screening for anxiety, depression, and/or ADHD at a young age in patients with CHD, regardless of disease severity. Furthermore, these data underscore the importance of recognizing potential racial or ethnic bias in diagnosing mental health in children with CHD, as well as enabling insurance coverage for

treating these disorders. In the future, researchers should examine if these findings are specific to patients with CHD versus other childhood chronic diseases and investigate earlier mental health interventions to reduce the burden of anxiety, depression, and ADHD in the population of individuals with CHD.

## ABBREVIATIONS

ACHD: adult congenital heart disease  
ADHD: attention-deficit/hyperactivity disorder  
CBT: cognitive behavioral therapy  
CHD: congenital heart disease  
CI: confidence interval  
ED: emergency department  
ICD-9: *International Classification of Diseases, Ninth Revision*  
NDD: neurodevelopmental disabilities  
NSV: nonsingle ventricle  
SV: single ventricle

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