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MENTAL HEALTH DISORDERS AND RISK OF HOSPITALIZATIONS AND EMERGENCY DEPARTMENT UTILIZATION AMONG INDIVIDUALS WITH CONGENITAL HEART DEFECTS

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MENTAL HEALTH DISORDERS AND RISK OF HOSPITALIZATIONS AND EMERGENCY DEPARTMENT UTILIZATION AMONG INDIVIDUALS WITH CONGENITAL HEART DEFECTS

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Abstract

MENTAL HEALTH DISORDERS AND RISK OF

HOSPITALIZATIONS AND EMERGENCY DEPARTMENT UTILIZATION

AMONG INDIVIDUALS WITH CONGENITAL HEART DEFECTS

By

Joy Chen

Background: Congenital heart defects (CHD) occur in approximately 1% of U.S. births and are comprised of a wide range of diagnoses ranging in severity and need for intervention. Mental health disorders (MHD) contribute significantly to the global burden of disease. Approximately one third of adults with CHD in the U.S. are reported to have a mood or anxiety disorder. Concurrent MHD with CHD has been linked to poorer physical health, lower quality of life, and increased hospitalizations.

Methods: This is a retrospective cohort study of patients, aged 14 to 55, with CHD who were seen at Emory Healthcare (EHC) and Children's Healthcare of Atlanta (CHOA) between January 1, 2010 and December 31, 2019. Bivariate analysis and multivariate logistic regression models were created to evaluate the impacts of MHD and CHD on hospitalizations and emergency department (ED) visits. Demographic factors such as age, sex, race and ethnicity, insurance, and rurality were also included.

Results: Females patients with co-occurring MHD had higher odds for hospitalizations than males regardless of whether CHD was categorized using a four anatomic groups scheme (aOR 4.63 95% CI [4.01-5.34] vs. 3.21 [2.72-3.79]) or collapsed into severe and non-severe (aOR 4.64 [4.02-5.35] vs. 3.22 [2.73-3.79]) or conotruncal and non-conotruncal (aOR 4.99 [3.78-6.62] vs. aOR 3.39 [2.44-4.72]). Urban patients with a MHD had higher odds for an ED visit when categorized by four anatomic groups (aOR 2.78, [2.33-3.32]) or by severe and non-severe (aOR 2.85 [2.40-3.37]), while rural patients did not. Finally, among those with conotruncal defects, Hispanic patients with co-occurring MHD had higher odds for an ED visit (aOR 8.39 [2.14-37.56]) than non-Hispanic white (aOR 2.28 [1.43-3.63]) and non-Hispanic black patients (aOR 2.83 [1.69-4.68]).

Conclusions: MHD have significant impacts on hospitalizations and ED visits. Various demographic and social factors such as sex, rurality, and race, also appear to have a role in this relationship.

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List of Abbreviations

ACHD	Adults with Congenital Heart Defects
ADHD	Attention Deficit Hyperactivity Disorder
aOR	Adjusted Odds Ratio
ASD	**S**ecundum Atrial Septal Defect
CHD	Congenital Heart Defects
CHOA	Children's Healthcare of Atlanta
COPD	Chronic Obstructive Pulmonary Disorder
cOR	Crude Odds Ratio
DORV	Double Outlet Right Ventricle
ED	Emergency Department
EHC	Emory Healthcare
FISMA	Federal Information Security Management Act
eHR	Electronic Health Records
NCHS	National Center for Health Statistics
HLHS	Hypoplastic Left Heart Syndrome
ICD-9-CM	International Classification of Diseases, Ninth Revision, Clinical Modification
ICD-10-CM	International Classification of Diseases, Tenth Revision, Clinical Modification
IRB	Institutional Review Board
IT	Information Technology
MHD	Mental Health Disorders
MI	Myocardial Infarction

NCHS	National Center for Health Statistics
NIMH	National Institute of Mental Health
OR	Odds Ratio
PFO	Patent Foramen Ovale
PII	Personal Identifiable Information
PPV	Positive Predictive Value
PTSD	Post-Traumatic Stress Disorder
RSPH	Rollins School of Public Health
ToF	Tetralogy of Fallot
U.S.	United States

CHAPTER 1: BACKGROUND

Congenital Heart Defects (CHD)

Defect Classifications and Population Based Surveillance Prevalence

Congenital heart defects (CHD) are birth defects that affect both the structure and function of the heart.[1] These defects are found in approximately 1% of live U.S. births and are comprised of a wide range of diagnoses that can impact the chambers, valves, veins and arteries, or a combination of these structures, within the heart.[2-5] Additionally, it has been reported that approximately 21% of individuals with CHD receiving healthcare have defects considered anatomically severe. Severe CHD typically requires surgical intervention within the first year of life and can have significant negative consequences if treatment is delayed. [3,6-8]

CHD are categorized in several different ways based on native anatomy and/or repaired anatomy. Several studies conducted on the prevalence of CHD categorize CHD into five main native anatomy severity groups, based on International Classification of Diseases, Ninth Revision, Clinical Modification codes (ICD-9-CM) and International Classification of Diseases, Tenth Revision, Clinical Modification codes (ICD-10-CM). These mutually exclusive groups are: 1) severe, also referred to as complex, is comprised of multiple defects that typically require surgical or catheter intervention within the first year of life; 2) shunt; 3) valve; 4) shunt and valve; and 5) other.[9,10] A U.S. based population surveillance study by Glidewell et al. (2018) sought to estimate the prevalence of these CHD categories.[9] They found that across three sites, the distribution of anatomic categories was similar, with severe CHD representing 13-21% of cases receiving healthcare. Shunt was the largest non-severe category, representing 37-45% of CHD cases, followed by valve which was 16-22%. Those with combined shunt and valve lesions comprised the rarest severity group, representing only 1-3%

of cases. Finally, 'Other' CHD represented 17-28% of CHD cases.[9] Similarly, a study by Lui et al. (2019) found that severe cases accounted for 17-28% of CHD cases receiving healthcare. Shunt was still the largest category, representing approximately 25% of cases, followed by valve at 16-29%, other at 5-12%, and shunt and valve at 2-4%.[10] Both the Glidewell and Lui studies did not include ICD-9-CM code 745.5, which represents both heart defect atrial septal defect (ASD) and normal variant patent foramen ovale (PFO), due to the low positive predictive value (PPV) of this code thus likely underrepresenting the proportion with shunt lesions.[11] Other codes were also excluded for non-CHD diagnoses such as congenital heart block, an electrical disturbance, not a structural heart defect. Additionally, they found that patients within the severe CHD category were more likely to have inpatient encounters, and that 5-25% of adolescents with complex CHD were hospitalized during the surveillance period.[10]

ICD-9-CM and ICD-10-CM codes, extracted from clinical and administrative electronic health records (eHR), are often used to identify CHD. Sometimes, the reliance on clinical and administrative data sources leads to high false positives, as some prior studies have found that ICD-9-CM codes may not always accurately identify patients with CHD.[9,11-14] The ICD-9-CM code groups typically associated with CHD are 745.xx-747.xx and the ICD-10-CM codes are Q20.x-Q28.x. While these codes encompass a wide range of diagnoses, they also contain conditions, as noted, that do not represent true CHD. ICD-9-CM code 745.5 is particularly challenging as it includes both secundum ASD, a true CHD, and PFO, a normal variant seen in about 25% of the population, which is not considered a CHD. A study by Rodriguez et al. (2018) found that of patients who had ICD-9-CM code 745.5 in isolation without another heart defect code, 36% of children and 80% of adults did not actually have a

CHD. Therefore, due to the lack of specificity of this particular ICD-9-CM code, it has been suggested that studies should exclude individuals who exclusively have this code without other more definitive CHD-related codes present in their eHR or administrative data during analysis.[10,14-16] Additionally, when looking at the accuracy of ICD-9-CM coding amongst various CHD anatomic groups, the 'Other' CHD grouping may be less representative of true CHD conditions. The overall PPV of having a CHD has been shown to increase by 10 percentage points from 76.4% to 86.5% after omitting the 'Other' CHD anatomic group (X^2=22.28, p<0.0001).[17] Overall, of patients with an ICD-9-CM code for complex CHD, 89.9% had a true CHD (and 10.1% did not have a CHD), and the corresponding PPV estimates were 86.7% for shunt, 83.0% for valve, and 44.4% for 'Other' CHD anatomic group (X^2=142.16, p<0.0001).[17]

Challenges in Care

As of 2010, it is estimated that over 2 million individuals are living with CHD in the U.S. and advancements in medicine have resulted in many of these individuals, even those with anatomically severe CHD, living into adulthood.[5,6,8,18-20] Prevalence estimates of CHD, as of 2010, for the U.S. population was 7.67 per 1000 for males, and 8.03 per 1000 for females.[8,20] A study by Raskind-Hood et al. (2019) used capture re-capture methodology to estimate prevalence of CHD among adolescents, 11-20 years of age, and adults, 21-64 years of age, residing within five metro-Atlanta countries. The estimated prevalence was 7.85 per 1,000 adolescents and 6.08 per 1,000 adults.[21]

As the population of individuals with CHD ages and the number of adults with CHD (ACHD) rises, there are increasing challenges in how to manage the long-term care of these patients. Transition of care to adult specialists, loss to follow-up from cardiology care, and

increased medical comorbidities all contribute to potential negative outcomes.[22-25] A study by Mackie et al. (2009) found that by their 18th birthday, 61% of individuals with CHD were no longer receiving cardiac follow-up. Even for patients with anatomically severe CHD, 21% were lost to follow-up by 18 years of age.[22] This poses a significant challenge as patients with CHD have been shown to be at increased risk for other comorbidities, particularly as they age. Data from the **C**ongenital **H**eart **S**urvey **T**o **R**ecognize **O**utcomes, **N**eeds, and well-bein**G** (CH STRONG study) found that compared to the general population, adults with CHD, aged 20-38 years, reported higher rates of congestive heart failure (4.3% vs. 0.2%), stroke (1.4% vs. 0.3%), and current clinical depressive disorders (15.1% vs. 8.5%), but lower rates of asthma (12.7% vs. 16.9%), rheumatologic conditions (3.2% vs. 8.0%) and a history of depression (14.2% vs. 22.6%). It was also found that compared to the general population, those with anatomically severe CHD reported lower rates of obesity (52.7% vs. 57.8%) and cancer (0.5% vs. 2.5%), and those with non-severe CHD reported higher rates of diabetes mellitus (3.7% vs. 2.0%).[26] Comorbid conditions may be underestimated in administrative data if the CHD diagnosis is not captured for an individual with CHD who is receiving care for a non-CHD condition.

Mental Health Disorders

Prevalence of Common Mental Health Disorders

Mental health disorders (MHD) contribute significantly to the global burden of disease.[27] They have been associated with poorer physical health and can be extremely costly to treat, often requiring long-term recurrent care.[28-30] In a pooled meta-analysis conducted by Steel et al. (2014), which estimated the global prevalence of various common MHD, lifetime prevalence of having any MHD was 32.2%, with mood and anxiety disorders reported at 9.6% and 12.9%, respectively;[31] mood disorders include such clinical diagnoses like major

depressive disorder, bipolar disorder, seasonal affective disorder, etc., and anxiety disorders include such clinical diagnoses like phobias, panic disorders, social anxiety disorders, etc. Other evaluations have reported similar rates for mood and anxiety disorders, such as Baxter et al. (2013) suggesting a global estimate of anxiety at 7.1% and Ferrari et al. (2013) reporting a prevalence of 4.7% for major depressive disorders.[3,32] Post-traumatic stress disorder (PTSD) has been reported at a lower prevalence, affecting approximately 3.5% of the general population.[33] Finally, the prevalence estimate for schizophrenia based on global burden of disease studies is approximately 0.28%.[34]

In the U.S, it is estimated that 21% of the population have a MHD, with 5.6% living with a serious mental illness.[35] Based on prevalence data from the National Institute of Mental Health (NIMH), 8.4% of adults had at least one major depressive episode in the previous year.[36] Approximately 19.1% of adults had an anxiety disorder in the past year with an estimated lifetime prevalence of 31.1%.[37] These numbers are higher than the global prevalence, however, they include a wide range of disorders including generalized anxiety, phobias, obsessive-compulsive disorder, and PTSD. Bipolar disorder was present in 2.8% of U.S. adults.[38] Finally, schizophrenia was reported in 0.25% of U.S. adults, which is consistent with global prevalence reports.[39]

Demographic and Socioeconomic Factors Impacting Mental Health

Differences in MHD prevalence and severity have been found to be associated with various demographic and socioeconomic factors. Sex appears to play a significant role, where women are twice as likely to be diagnosed with depression and anxiety, while men are more likely to have aggressive behavior, oppositional defiant disorder, and attention deficit hyperactivity disorder (ADHD).[40-43] Bipolar disorder II is also more common in women, and

women with bipolar disorder have higher risk of developing depression, having rapid cycling, and having comorbid anxiety disorders and PTSD.[44-48] Comparatively, men with bipolar disorder are more likely to have manic episodes and unipolar mania.[49] Sex differences have also been well documented in schizophrenia for age of onset, symptoms, and treatment effects. Females have a considerably later age of onset and have a second peak at around 40-50 years old.[50-52]Additionally, men with schizophrenia appear to have more negative symptoms and more severe clinical features, whereas women are shown to have later age of onset and present with more positive psychotic symptoms.[53,54] Females also appear to show better treatment response and less hospitalizations compared to males.[52,55]

Differences in MHD have also been observed based on race and ethnicity. Various U.S. based studies have found that compared to white Americans, African Americans, Asian Americans and Hispanic Americans have increased depressive symptoms independent of socioeconomic status.[56-60] When looking at the presence of any psychiatric disorder in the past year, the prevalence was 22.6% for whites, 17.3% for African Americans, 13.9% for Asian Americans, 18.4% for Hispanics, and 35.8% for those reporting two or more races.[61] While some studies show lower risk of lifetime prevalence of MHD for African Americans and Hispanics compared to whites, they appear to have longer course of illness and greater disability from mental illness.[62] Some potential reasons for these disparities are lack of access to appropriate care and inadequate insurance coverage of mental health resources.[63-65]

Finally, the location of residence for patients also appears to play a role in mental health, primarily in terms of access to quality care. It is estimated that 20% of the U.S. population lives in a rural area, with about 6.5 million individuals from these areas living with a mental illness.[66,67] While the prevalence of MHD for patients living in rural versus urban

areas is similar, patients in rural areas receive care less frequently and have limited access to providers that specialize in mental health, which can lead to more severe illness.[68-70]

Age of Onset

Research has found that MHD often have an early age of onset and have significant impacts on adolescents, contributing to a large burden of disease for young people.[71-73] Among 10-24 year-olds, neuropsychiatric disorders represented 45% of all disability adjusted life years.[74] Anxiety disorders are among the most common mood disorders in adolescents and have a reported prevalence of 20-32% as well as a median age of onset at 6 years old.[75] Early onset of anxiety disorders was also found to be related to more severe and disabling forms of mood disorders, which have a reported prevalence of 14.3% among adolescents and an age of onset at 13 years old.[17,76] This poses increased challenges as early age of onset has been shown to be associated with more chronic disease, longer duration of disease, increased severity of disease, increased hospitalizations, and increased latency to treatment.[77-82] Psychotic disorders such as schizophrenia have a later age of onset compared to mood and anxiety disorders, however, age at onset is within early adulthood around 22-29 years old, with 70% of patients reporting onset before the age of 25.[83-85]

Congenital Heart Defects and Mental Health Disorders

Depression and Anxiety

It is reported that approximately one third of ACHD in the U.S. who participate in structured psychiatric interviews meet diagnostic criteria for a mood or anxiety disorder.[86-88] Depression and anxiety have been associated with adverse cardiovascular outcomes that often exacerbate the already increased morbidity and mortality for the aging CHD population.[89-91] Risk factors for depression and anxiety for these patients include neurocognitive repercussions

of CHD, functional status, and psychosocial factors.[92-98] Anatomic severity and age may also play a role; however, severity may not capture the true cause of disease burden, and age is likely associated with distress built over time.[97,99,100] Patients with CHD face unique stressors such as invasive surgeries throughout their lifetimes, the financial burden of long-term care, and uncertainty of their futures, which contribute to elevated emotional distress.[94,101] Therefore, it is important to understand the prevalence and risk factors for depression and anxiety among patients with CHD to help understand their specific psychosocial needs.

Depression and anxiety have been shown to be the most common MHD among patients with CHD. A study by Bromberg et al. (2003) recruited patients with CHD who physicians felt were well-adjusted.[88] Alarmingly, they found that based on diagnostic interviews, 36% of participants met DSM-IV criteria for a psychiatric disorder, with depression as the most prevalent at 27.3%, followed by generalized anxiety disorder at 9.1%. This study also found that patients with depression were more likely to have more anatomically severe CHD.[86] These findings are supported by a more recent surveillance study of individuals with CHD in Colorado which found the most prevalent categories of mental illness in adults were mood and anxiety disorders, especially among those with moderate or complex CHD compared to patients with simple lesions.[102] In this study, a moderate CHD diagnosis included Ebstein Anomaly of tricuspid valve, subaortic stenosis, coarctation, aortic stenosis, pulmonary artery anomaly, and primum ASD, while complex CHD conditions included common truncus, transposition of the great arteries, congenitally corrected transposition, double outlet right ventricle (DORV), tetralogy of Fallot (ToF), single ventricle, endocardial cushion defect, pulmonary valve atresia, tricuspid atresia, hypoplastic left heart syndrome (HLHS), interrupted aortic arch, or total anomalous pulmonary venous return. In another study conducted by

Gleason et al. (2019), similarly high rates of MHD were reported with 43% of participants with CHD having elevated symptoms on at least one subscale of depression or anxiety and 12% reporting elevations on both.[103] Anxiety was more commonly reported than depression, with 31% of patients reporting anxiety alone. Depression was reported alone in less than 1% of participants and was almost entirely present (94%) in combination with elevated anxiety. However, unlike previous studies, no differences were found for the severity of CHD between those with anxiety, depression, or both.[103]

The impact of physical functioning on mental health and quality of life for individuals with various types of CHD was investigated by Moons et al. (2021).[104] They found that patients with cyanotic heart disease or Eisenmenger syndrome had the lowest physical functioning, the worst depression and anxiety symptoms, as well as the lowest quality of life scores. Alternatively, patients with coarctation of the aorta had the highest physical functioning and lowest depression symptoms. Similarly, patients with isolated aortic valve disease had the lowest anxiety symptoms and highest quality of life scores.[104] Moon et al. (2021) suggest that invasive surgeries including the need for cardiopulmonary bypass, in particular, detrimentally impacts the mental health of those with CHD. This is supported by some evidence in the literature, particularly for patients with certain defects who may require more surgical interventions which could lead to increased risk for neurologic and cognitive side effects.[95,97] Additionally, history of cyanosis and other neurocognitive events have been shown to contribute to decreased coping skills and reduced executive functioning for congenital heart patients, which, in turn, may lead to a higher risk for these patients for MHD such as depression.[105-108]

Finally, a reduction in psychosocial functioning has also been shown to contribute to emotional distress in patients with CHD. A Japanese study by Enomoto et al. 2013 examined psychosocial factors, mental health, and quality of life between defect subgroups and healthy controls. They found that patients with CHD were more dependent on caretakers, had lower self-confidence, and lower social skills for problem solving. Independence and self-esteem were highly correlated and positively associated with problem solving, which, in turn, positively impacted mental health scores.[92] These findings are supported by Thomet et al. (2018) who found that higher self-efficacy was related to decreased anxiety and depression and higher quality of life.[109] Other studies have pointed to lower perceived social support, unemployment, and health competence to impact anxiety and depression.[99,109,110]A study by Leslie et al. (2020) examined the effect of perceived health competence on depression and anxiety. Data revealed that lower levels of perceived health competence at baseline was predictive of anxiety and depression at three years. Additionally, patients with lower perceived health competence showed greater impairment of psychosocial functioning at follow-up which could contribute to decreased confidence in the ability to manage their own CHD symptoms.[93]

These studies suggest that depression and anxiety are highly prevalent for individuals with CHD. The risk factors involved are complex and multifactorial, spanning various aspects of life. It is of increasing importance to understand the gaps in mental health care for this population since research suggests that patients with MHD have higher inpatient hospitalization and healthcare needs.[102]

Post-Traumatic Stress Disorder (PTSD)

Patients with CHD, particularly those with severe defects, often undergo invasive medical procedures from a young age and must learn to manage their chronic medical

condition which includes regular cardiac clinic visits, medications, emergency department (ED) visits and hospitalizations. The emotional distress, physical pain, disruption of 'normal' life, medical trauma, and uncertainty about the need for future medical interventions can contribute to the development of PTSD.[111-114] However, the number of studies examining the association between CHD and PTSD are limited, many with small sample sizes. Reported rates of PTSD among patients with CHD appear to be relatively high, with some studies reporting prevalence up to 52%.[115,116] A study by Connolly et al. (2004) consisted of 43 children who underwent cardiac surgery with 12% meeting diagnostic criteria for PTSD.[115] Similarly, Toren et al. (2007) recruited 31 adolescents with a history of surgery for congenital cyanotic heart disease and found that 29% likely had PTSD. Interestingly, the mean time difference between cardiac surgery and PTSD assessment was 13.7 years, suggesting that PTSD persists long after surgical intervention.[116] Finally, in a study examining the impact of illness uncertainty associated with increased anxiety and lower quality of life among adolescents, 24% of patients with CHD had clinically significant PTSD.[113,114] The study reported that participants who reported severe PTSD treated uncertainty as a danger and this contributed to their stress and negative emotions. Participants were reported to have intrusive thoughts, recurring nightmares about aspects of their treatment, as well as feelings of reliving the traumatic events.[113]

Additional research also suggests that PTSD is associated with negative outcomes in cardiac patients such as increased hospitalizations and myocardial infarctions (MI), as well as negative mental health consequences such as increased suicidality, lower psychosocial functioning, and increased prevalence of mood and anxiety disorders.[33,117-121] Various risk factors for PTSD among patients with CHD have been identified. For instance, a study by Eslami et al. (2017) found that patients with CHD who had a history of cardiac surgery were

more likely to develop PTSD.[122] Similarly, Deng et al. (2016) found that having a recent cardiac surgery was associated with PTSD.[123] Connolly et al. (2004) reported that patients with an intensive care unit stay longer than 48 hours reported increased rates of PTSD symptoms.[115] In addition to traumatic medical experiences, various studies have found that MHD, particularly depression, can lead to increased vulnerability to PTSD.[33,122-124] Based on studies regarding the prevalence of PTSD among patients with CHD, the potential negative impact on outcomes, and the relationship to medical trauma and mental health, PTSD in individuals with CHD warrants future research investigating these relationships.

Schizophrenia and other Psychotic Disorders

The most common chromosomal microdeletion syndrome, 22q11.2DS, has an estimated prevalence of 1 in 3,000 to 1 in 6,000 live births.[125-127] It is the second-most common cause of CHD accounting for 10-15% of patients with ToF.[128,129] Additionally, the majority of patients with CHD due to 22q11.2DS have conotruncal heart defects, or malformations of the outflow tract, which occur frequently, approximately 60% of the time, in conjunction with anomalies of the aortic arch and/or pulmonary arteries.[130] In fact, CHD represents the largest cause of mortality among children with 22q11.2DS at approximately 87%.[131]

In addition to its association with CHD, patients with 22q11.2DS are at a significantly increased risk of developing various MHD. Most notably, 22q11.2DS is the strongest known genetic risk factor for schizophrenia.[132] Approximately 25% of individuals with 22q11.2DS are diagnosed with schizophrenia.[133] There is no known difference in the manifestation of schizophrenia for patients with 22q11.2DS as age of onset, symptoms, and treatment response appears to be the same for those without.[134-136] In addition, 22q11.2DS has also been associated with increased rates of anxiety, however, its impact on bipolar disorder and depression are still

unclear.[137,138] Based on these findings, future research investigating the relationship between patients with CHD with conotruncal defects and the development of schizophrenia and other psychotic disorders is needed, including what impact this may have on their health outcomes.

CHAPTER II: METHODS

Hypothesis

1) Do patients with a congenital heart defect (CHD) and a mental health disorder (MHD) have higher odds of hospitalizations and emergency department (ED) visits compared to patients with CHD without MHD?
2) Are patients with anatomically severe CHD and MHD more likely to have higher rates of hospitalization and ED visits compared to patients with non-severe CHD and MHD?

Specific Aims

1) Determine rates of hospitalization and ED visits among patients with CHD with and without MHD.
2) Develop a multivariable logistic regression model for the relationship between MHD and hospitalizations and ED visits.

Study Design and Population

This is a retrospective cohort of patients with CHD who were seen at least once over a ten-year window from January 1, 2010 to December 31, 2019 at one of two data source providers, Emory Healthcare (EHC) and Children's Healthcare of Atlanta (CHOA).

The study is a secondary data analysis of a healthcare dataset of adolescents and adults with CHD extracted from the Emory University Congenital Heart Disease Repository (IRB 00064051 and STUDY00000121) housed at the Rollins School of Public Health (RSPH), Emory University. The secondary study population includes patients, ages 14-55 years, who have at least one of the total 84 CHD-related ICD codes, ICD-9-CM (40) or ICD-10-CM (44) codes (Appendix A), and who had sought healthcare evidenced by at least one encounter at

EHC, CHOA or both. In addition, the study population also either had, or did not have, one or more of seven MHD as defined in Appendix B.

Data Management and IRB

The parent study (Repository) had approval from Emory University's Institutional Review Board (IRB) on 03/16/2020 (IRB#00000121); the current study was approved by the Emory University IRB on 01/27/2022 (IRB#00003955). To ensure data confidentiality, data were housed securely and analyzed at the Emory University, RSPH. The data was password protected, with only the researchers having access to the secure drive. The final analytic dataset was de-identified, with no patient identifiers included.

All data reside on a Federal Information Security Management Act (FISMA)-compliant server housed within the Emory University, RSPH Information Technology (IT) network; the server is maintained by authorized RSPH IT personnel and only Emory researchers affiliated with these two surveillance projects have access to the specific project drive, the subdirectories of the CHD data repository, and the customized analytic dataset for this study. Data included in the analytic dataset were previously cleaned and formatted in a uniform fashion, and all demographic and encounter-level records were de-duplicated prior to construction of the analytic dataset. Personal Identifiable Information (PII) for each patient was removed and replaced with a proxy unique identifier. To maintain confidentiality and privacy; PII was not included in the analytic dataset.

Inclusion and Exclusion Criteria

The initial study population of patients with a CHD who had a healthcare encounter between January 1, 2010 and December 31, 2019 was 43,109. Once patients who were less than 14 years of age and greater than 55 years of age (n=29,253) and those classified as having

'Other' CHD (n=344) were excluded, the final study sample was reduce to 13,512. This sample included patients between the ages of 14 and 55 years old, diagnosed with CHD as defined in Appendix A, who were seen at least once over a ten-year window from January 1, 2010 to December 31, 2019 (Figure 1). To be identified as having a CHD, patients have at least one of the 84 CHD-associated ICD-9-CM and/or ICD-10-CM codes (Appendix A); there are 40 ICD-9-CM codes and 44 ICD-10-CM codes (Appendix A). Patients categorized as having an 'Other' CHD were excluded. Additionally, to be identified as having a mental health disorder (MHD), patients must have at least one of the seven MHD disorders listed in Appendix B, defined by ICD-9-CM or ICD-10-CM codes (Appendix B).

Outcome Variables

The outcomes or dependent variables were: 1) having a hospitalization between January 1, 2010 and December 31, 2019; and 2) having an ED visit between January 1, 2010 and December 31, 2019. Having a hospitalization from 2010-2019 was defined as having at least one hospitalization event during the surveillance period, consisting of a stay of two or more days. The outcome was binary and coded as '0' for those with no hospitalizations and '1' for those who had at least one hospitalization. Having an ED visit from 2010-2019 was defined as having at least one ED visit during the surveillance period. The outcome was binary and coded as '0' for those with no ED visits and '1' for those who had at least one ED visit.

Exposure Variables

Any Mental Health Disorder (MHD)

The main exposure variable in this study was the presence or absence of a MHD during the 10-year study period. This variable was constructed to represent the history of having any MHD based on the presence of at least one of the seven disorders noted

below and in Appendix B, which include: 1) depressive disorders; 2) anxiety disorders; 3) bipolar disorders; 4) PTSD; 5) personality disorders; 6) neurodevelopmental and behavior disorders; and 7) psychotic disorders and schizophrenia during the 10-year study period. This variable was categorized dichotomously as '0' for those having none of the seven mental health disorders or '1' for those having at least one of the seven aforementioned mental health disorders diagnosed during the 10-year study period. These exposure variables were considered because they are well established risk factors for adverse outcomes in teens and adults with CHD.

Depressive Disorders

Depressive disorders or depression were categorized dichotomously as '0' for those with no diagnosis of a depressive disorder and '1' for those with a diagnosis of a depressive disorder as defined in Appendix B. Depressive disorders were operationalized by the presence of at least one of 54 codes (at least one of 25 ICD-9-CM codes and/or at least one of 29 ICD-10-CM codes). Those without depression served as the reference group during analysis.

Anxiety Disorders

Anxiety disorders were categorized dichotomously as '0' for those with no diagnosis an anxiety disorder and '1' for those with a diagnosis of an anxiety disorder as defined in Appendix B. Anxiety disorders were operationalized by the presence of at least one of 26 codes (at least one of 13 ICD-9-CM codes and/or at least one of 13 ICD-10-CM codes). Those without an anxiety disorder served as the referent group during analysis.

Bipolar Disorders

Bipolar disorders were categorized dichotomously as ‘0’ for those with no diagnosis of bipolar disorder and ‘1’ for those with a diagnosis of bipolar disorder as defined in Appendix B. Bipolar disorders were operationalized by the presence of at least one of 77 codes (at least one of 38 ICD-9-CM codes and/or at least one of 39 ICD-10-CM codes). Those without bipolar disorder served as the referent group during analysis.

Post-Traumatic Stress Disorder (PTSD)

PTSD was categorized dichotomously as ‘0’ for those with no diagnosis of a trauma disorder and ‘1’ for those with a diagnosis of trauma disorder as defined in Appendix B. PTSD was operationalized by the presence of at least one of 85 codes (at least one of 41 ICD-9-CM codes and/or at least one of 44 ICD-10-CM codes). Those without PTSD served as the referent group during analysis.

Personality Disorders

Personality disorders were categorized dichotomously as ‘0’ for those with no diagnosis of personality disorder and ‘1’ for those with a diagnosis of personality disorder as defined in Appendix B. Personality disorders were operationalized by the presence of at least one of 32 codes (at least one of 14 ICD-9-CM codes and/or at least one of 18 ICD-10-CM codes). Those without personality disorder served as the referent group during analysis.

Neurodevelopmental and Behavior Disorders

Neurodevelopmental and Behavior disorders were categorized dichotomously as ‘0’ for those with no diagnosis of either a neurodevelopmental disorder or an impulse and behavior disorder and ‘1’ for those with a diagnosis of either a neurodevelopmental disorder or an impulse and behavior disorder as defined in Appendix B.

Neurodevelopmental and Behavior disorders were operationalized by the presence of at least one of 53 codes (at least one of 23 ICD-9-CM codes and/or at least one of 30 ICD-10-CM codes). Those without an adjustment disorder served as the referent group during analysis.

Psychotic Disorders and Schizophrenia

Psychotic disorders and schizophrenia were categorized dichotomously as '0' for those with no diagnosis of a psychotic disorder or schizophrenia and '1' for those with a diagnosis of psychotic disorder or schizophrenia as defined in Appendix B. Psychotic disorders and schizophrenia were operationalized by the presence of at least one of 47 codes (at least one of 21 ICD-9-CM codes and/or at least one of 26 ICD-10-CM codes). Those without schizophrenia served as the referent group during analysis.

Covariates

Covariates included in this study were CHD anatomic severity group, conotruncal defects in particular; age, sex, race/ethnicity, residency, and health insurance coverage. These covariates were considered because they are either well established risk factors for adverse outcomes in ACHD or help us establish the impacts of MHD on teens and adults with CHD.

CHD Severity

CHD severity was classified into four categories initially modeled after Marelli et al.'s (2007) hierarchical classification of CHD based on ICD-9-CM codes, and later reconceptualized by congenital heart defect clinicians from three U.S. Centers for Disease Control and Prevention (CDC) congenital heart disease (CHD) surveillance projects iterations, the "Surveillance of Congenital Heart Disease in Adolescents and Adults" (CDC-RFA-DD12-1207), the "Surveillance of Congenital Heart Disease Across

the Lifespan" (CDC-RFA-DD15-1506), and the "Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults" (CDC-RFA-DD19-1902A) Appendix A): 1) severe; 2) shunt and valve; 3) shunt; and 4) valve; the purpose of these projects was to devise and increase population-based tracking of individuals with CHD. The four CHD anatomic groups were collapsed into a dichotomous variable, severe versus non-severe, where the categories of shunt and valve, shunt, and valve were combined into a single category called non-severe. Severe was coded as '1' and non-severe was coded as '0'. During analyses using four CHD categories, the shunt group served as the reference group. For analyses where the dichotomous variable for CHD was applied, non-severe served as the reference group.

Conotruncal Defects

Conotruncal defects were categorized dichotomously as '0' if not present and '1' for patients who had any of the following severe CHD diagnoses: 1) Hypoplastic left heart syndrome (HLHS); 2) Common truncus; 3) Double outlet right ventricle (DOLV); 4) tetralogy of Fallot (ToF); 5) Transposition of the great arteries (TGA); and 6) Interrupted aortic arch (Appendix C). Those without conotruncal defects served as the referent group during analysis.

Age

Patients in this study were between the ages of 14 and 55 years old, diagnosed with at least one of the ICD-9-CM or ICD-10-CM CHD-related codes identified in Appendix A, within the ten-year window from January 1, 2010 to December 31, 2019. Age was treated categorically and divided into three birth cohorts: 14-19 years of age = '1', 20-29 years of age = '2' and 30-54 years of age = '3'.

Sex

Sex was categorized dichotomously as ‘0’ for females and ‘1’ for males. Females served as the reference group during analysis.

Race and Ethnicity

Race and ethnicity were combined and classified into the following five categories: ‘1’ for non-Hispanic whites, ‘2’ for non-Hispanic blacks, ‘3’ for Hispanics, ‘4’ for ‘Other’ (i.e., American Indian/Alaskan Native, Asian, or Native 21 Hawaiian/other Pacific Islander), and ’5’ for unknown. Non-Hispanic whites served as the reference group during analysis.

Insurance Type

Insurance type was categorized into the following five categories: ‘1’ for any public insurance, ‘2’ for private insurance only, ‘3’ for self-pay or uninsured, ‘4’ for ‘Other’, and ‘5’ for unknown. Any public insurance served as the reference group during analysis.

Rurality

Rurality was determined using the National Center for Health Statistics (NCHS) classification scheme based on zip code and classified into six area types: 1) large central metro; 2) large fringe metro; 3) medium metro; 4) micropolitan; 5) non-core; and 6) small metro. These six categories were further collapsed into urban and rural where categories 1-4 represented urban and categories 5 and 6 represented rural. This dichotomous rurality variable was categorized as ‘0’ for those living in an urban area, and ‘1’ for those living in a rural area. Urban residence served as the reference group during analysis.

Statistical Analysis

All analyses were conducted using RStudio version 1.4.1717 with an alpha level of 0.05 to determine statistical significance. Simple descriptive statistics were performed for each predictor variable and covariate. Frequencies and percentages were computed for categorical variables by both CHD severity schemes, conotruncal defects, sex, race, ethnicity, insurance type, and rurality for patients with and without a MHD. Prevalence of depressive disorders, anxiety disorders, bipolar disorders, PTSD, personality disorders, neurodevelopmental and behavior disorders, and psychotic disorders and schizophrenia for patients with CHD were reported.

Bivariate analysis was conducted using chi-square tests to determine any differences in characteristics between patients with a hospitalization and those without, as well as for those with an ED visit and those without. Bivariate analysis was also conducted to find differences in patient characteristics for those with at least one MHD and those without. Differences in hospitalizations, ED visits, and MHD were obtained through chi-square analysis.

Univariate logistic regression models were used to determine the odds ratio (OR) for hospitalizations and ED visits among patients with the presence of any MHD and all other covariates. Three fully adjusted models were created to investigate the impacts of CHD classified in 3 ways: by CHD anatomic group, by severe and not severe, and conotruncal and not conotruncal among only severe CHD. From these models, interaction was assessed using the Backwards Elimination method and all non-significant interaction term were dropped from further analysis. Potential confounders were then evaluated using all possible subsets (Gold Standard model approach) where confounding was considered present based on a greater than 10% change in the reported OR. Logistic regression was used to determine: 1) the odds of

having a hospitalization for patients with any MHD compared to those without and 2) the odds of having an ER visit for patients with any MHD compared to those without.

CHAPTER III: RESULTS

Descriptive Statistics

Overall, a total of 13,512 patients were included in this study. Of these, 18.47% (n=2,496) experienced at least one hospitalization event between January 2010 and December 2019, and 6.80% (n=919) experienced at least one emergency department (ED) visit (Table 1). At least one MHD was reported for 20.40% (n=2,757) of patients with CHD, with anxiety disorders being the most commonly reported in 10.58% (n=1,413) of the patients, followed by 6.94% (n= 938) with depressive disorders, 6.30% (n=851) with neurodevelopmental and behavioral disorders, 4.28% (n=578) with PTSD, 1.18% (n=159) with bipolar disorders, 0.85% (n=115) with psychotic disorders and schizophrenia, and 0.70% (n=94) with personality disorders. CHD anatomic grouping was evaluated in 3 ways, by: 1) four categories (severe, shunt and valve, shunt, and valve) (Appendix A); 2) severe vs. non-severe (shunt and valve, shunt, and valve); and 3) for those with severe CHD, conotruncal defects vs. non-conotruncal defects (Appendix C). When CHD was analyzed applying the four anatomic groupings, the majority of CHD patients had shunt lesions, 37.18% (n=5,024), followed by 28.45% (n=3,844) with valve lesions, 27.04% (n=3,654) with severe CHD, and lastly, 7.33% (n=990) with a combination of shunt and valve defects. When CHD was collapsed into severe vs. non-severe, 27.04% (n=3,654) had a severe CHD and 72.96% (n=9,858) had a non-severe CHD. Finally, among those patients with severe CHD, 53.64% (n=1,960) had a conotruncal defect and 46.36% (n=1,694) had a non-conotruncal defect (Table 1).

Demographic factors included age, sex, race and ethnicity, rurality, and health care insurance coverage (Table 1). Age was categorized into three groups with 36.00% (n=4,864) between ages14-19-years-old, 28.68% (n=3,875) between ages 20-29-years-old, and 35.32%

(n=4,773) between ages 30-54-years-old. Overall, sex was close to evenly distributed with 48.75% (n=6,587) males. Race and ethnicity were classified into 5 categories with non-Hispanic whites representing 51.64% (n=6,978) of patients, followed by 24.56% (n=3,318) for non-Hispanic blacks, 6.16% (n=833) for Hispanics, and 3.55% (n=480) of patients reporting 'Other' as their race/ethnicity which included American Indian/Alaskan Native, Asian, and Native Hawaiian/Pacific Islander, and multi-racial. The majority of patients resided in urban areas, 80.88% (n=10,929), compared to 11.43% (n=1,544) who lived in rural areas. The majority of patients had public insurance, 78.92% (n=10,663), sometime during the 10-year study period.

Chi-square tests were conducted to assess the associations between covariates and both outcomes separately, having any hospitalization events or any ED visits (Table 2). When evaluating hospitalizations, patients with a MHD had significantly higher rates of hospitalization compared to those without a MHD (36.42% vs 13.87% respectively, X^2=739.05, p<0.001). All three CHD anatomic grouping schemes were significantly associated with having at least one hospitalization. In Table 2, for the 4-level CHD scheme, patients with severe CHD (22.06%) had a higher occurrence of hospitalization compared to patients with shunt and valve lesions (17.98%), shunt lesions (18.37%), and valve lesions (15.32%) X^2=56.71, p<0.001). Similarly, those with severe CHD had a higher occurrence of hospitalization compared to patients with non-severe lesions (22.06% vs. 17.14%, X^2=42.43, p<0.001), and for those with severe CHD lesions only, those with conotruncal defects had higher rates of hospitalization compared to those with non-conotruncal defects (26.58% vs. 17.10%, X^2=99.47, p<0.001). Hospitalization rates also differed by age with only 0.49% of the 14-19-year-olds experiencing at least one hospitalization event over the study period compared

to 13.73% of the 20-29-year-olds and 40.65% of the 30-54-year-olds, X^2=2660.02, p<0.001. Females had higher rates of hospitalization compared to males (20.06% vs. 16.81%, X^2=23.49, p<0.001). Additionally, there were significant differences in hospitalizations by race with non-Hispanic black patients having the highest rate (22.03%) of hospitalization, followed by those reporting unknown race (20.65%), those reporting their race as 'Other' (17.71%), non-Hispanic whites (17.25%), and lastly, Hispanics (9.96%) (X^2=81.01, p=<0.001). Having at least one hospitalization also differed by rurality with 17.42% of patients who lived in rural areas having at least one hospitalization compared to 18.14% of patients residing in urban areas and 23.48% of patients living in areas classified as unknown (X^2=19.24, p<0.001). Finally, 22.53% of patients with public insurance had at least one hospitalization. However, variation in health insurance coverage for the sample was limited. There were very few patients who had had a hospitalization who had private health insurance only, who indicated that they were self-pays or uninsured, or who reported 'Other' as their health insurance coverage.

When evaluating ED visits, patients with a MHD had significantly higher rates than those without a MHD (13.86% vs. 4.99% respectively, X^2=270.53, p<0.001) (Table 2). For the 4-level CHD anatomic grouping, while the differences were small, patients with shunt defects had a highest occurrence of ED visits compared to patients with severe lesions, shunt and valve lesions, or valve lesions (8.60% vs. 5.69% vs. 5.45% vs. 5.85% respectively, X^2=40.98, p<0.001). In contrast, patients with severe CHD had a lower occurrence of ED visits compared to those with non-severe CHD (5.69% vs. 7.21%, X^2=9.48, p<0.002), and for those with severe CHD, those with conotruncal defects had a lower rate of ED visits than those with non-conotruncal defects (5.66% vs. 6.99%, X^2=4.48, p<0.034). ED visits also differed by age group where only 0.45% of 14-19-year-olds had an ED visit compared to 6.25% of 20-29-year-olds

and 13.72% of 30-54-year-olds (X^2=671.96, p<0.001). Females had higher rates of ED visits compared to males (8.13% vs 5.4%, X^2=39.13, p<0.001). Additionally, ED visit rates differed by race with non-Hispanic blacks having the highest rates (11.93%), followed by 'Other' race (6.67%), non-Hispanic whites (5.43%), those with unknown race (4.1%), and lastly, Hispanics (4.08%) (X^2=190.27, p<0.001). ED visits also differed by rurality status with 7.66% of patients living in urban areas reporting any ED visits compared to 2.01% of those living in rural areas and 4.91% with unknown urban-rural status (X^2=74.51, p<0.001). Finally, 8.23% of patients with any public insurance had an ED visit. As with hospitalizations, there were very few patients who had any ED visits who had private health insurance only, who indicated that they were self-pays or uninsured, or who reported 'Other' as their health insurance coverage.

Lastly, the association between all covariates and having any MHD was evaluated (Table 2). When the 4-level CHD anatomic group was assessed, having a MHD differed with severe CHD patients reporting the highest rate of MHD (23.34%), followed by patients with shunts (20.70%), shunts and valves (20.10%), and those with valve lesions (17.30%) (X^2=42.59, p<0.001). Similarly, patients with severe CHD had higher rates of MHD compared to patients with non-severe CHD (23.34% vs. 19.31%, X^2=26.41, p<0.001), and for those patients with severe CHD, those with conotruncal defects were more likely to have MHD compared than those with non-conotruncal defects (25.56% vs. 19.53%, X^2=37.17, p<0.001). Having a MHD also differed by age with 17.68% of 14-19 year-olds compared to 18.25% of 20-29 year-olds and 24.93% of 30-54 year-olds reported having a MHD (X^2=93.58, p<0.001). Females were more likely to have any MHD compared to males (21.42% vs 19.34%, X^2=8.81, p=0.002). Additionally, having a MHD differed by race with non-Hispanic whites having the highest rates (23.32%), followed by non-Hispanic blacks (20.04%), Hispanics (17.65%), those

reporting ‘Other’ race (14.79%), and lastly, those with an unknown race (12.98%) (X^2=114.50, p<0.001). Having a MHD also differed by rurality with 20.92% of rural patients having MHD compared to 20.72% of urban patients and 16.27% with unknown as their rural/urban status (X^2=11.90, p=0.003). Finally, 20.82% of patients covered by any public insurance over the 10-year study period had a MHD compared to 16.84% of patients with private insurance only, but this effect was not statistically different (X^2=3.71, p=0.1561).

Logistic Regression Models

Univariate logistic regression revealed that the presence of a MHD significantly increased the odds of having any hospitalizations (cOR 3.97, 95% CI 3.57-4.42) and any ED visits (cOR 2.97, 95% CI 2.57-3.43) (Table 3). When the 4-level CHD classification was assessed, having a severe CHD increased the odds for having any hospitalizations (cOR 1.13, 95% CI 1.01-1.26) compared to those with shunt lesions, while having a valve defect was protective (cOR 0.72, 95% CI 0.64-0.81). In contrast, patients with severe CHD were less likely to experience any ED visits (cOR 0.53, 95% CI 0.45-0.64), as were patients with shunt and valve defects (cOR 0.64, 95% CI 0.47-0.85) or valve lesions (cOR 0.60, 95% CI 0.50-0.71), when compared to those with shunt lesions. When CHD was collapsed into severe CHD and non-severe CHD, patients with severe lesions were more likely to have any hospitalizations (cOR 1.27, 95% CI 1.15-1.41) and less likely to have had any ED visits (cOR 0.67, 95% CI 0.57-0.79). Additionally, among patients with severe CHD, patients with conotruncal defects had higher odds of hospitalization (cOR 1.75, 95% CI 1.55-1.98) and lower odds of having any ED visits (cOR 0.71, 95% CI 0.57-0.87).

In addition, in Table 3, age was analyzed omitting the 14-19-year-olds age group due to insufficient cell size. Compared to 20-29-year-olds, the 30-54-year-olds had higher odds for

hospitalization (cOR 4.30, 95% CI 3.86-4.80) and ED visits (cOR 2.39, 95% CI 2.05-2.79). Females were more likely to have had any ED visits (cOR 1.37, 95% CI 1.19-1.58), but sex was not associated with hospitalizations. Compared to non-Hispanic whites, non-Hispanic blacks were more likely to have had any hospitalizations (cOR 1.54, 95% CI 1.37-1.72) and ED visits (cOR 2.67, 95% CI 2.29-3.11); those reporting 'Other' race or unknown race were excluded from this analysis due to small cell size. Finally, those living in rural areas were less likely to have had ED visits (cOR 0.27, 95% CI 0.18-0.38) compared to those living in an urban area, but living in a rural area was not associated with hospitalizations.

Adjusted multivariate logistic regression for hospitalizations and ED visits, both unstratified and stratified by their individual effect modifiers, were performed separately for each of the three different CHD categorization schemes: by the 4-level anatomic CHD scheme (Tables 4a and 4b), by the dichotomous severe vs. non-severe CHD classification (Tables 5a and 5b); and lastly, by conotruncal defects vs. non-conotruncal defects, for those patients with severe CHD only (Tables 6a and 6b). Adjusted analysis with the 4-level anatomic CHD group included revealed that patients with co-occurring MHD were more likely to have had any hospitalizations (aOR 4.01, 95% CI 3.50-4.60) and any ED visits (aOR 2.73, 95% CI 2.30-3.22) (Table 4a and Table 4b, respectively). Compared to those with shunt defects, patients with severe CHD had higher odds for hospitalization (aOR 1.45, 95% CI 1.24-1.69), while patients with severe CHD (aOR 0.63, 95% CI 0.51-0.78) and those with shunt and valve defects (aOR 0.66, 95% CI 0.45-0,94) had lower odds for ED visits (Tables 4a and 4b, respectively). Patients in the older 30-54-year-old age group had higher odds for both hospitalization (aOR 5.87, 95% CI 5.14-6.73) and ED visits (aOR 2.68, 95% CI 2.25-3.21) (Tables 4a and 4b, respectively). Females were less likely to have had any hospitalizations

(aOR 0.80, 95% CI 0.70-0.91), and there was no effect of sex on ED visits in this multivariable model. Compared to non-Hispanic white patients, non-Hispanic black patients were at increased odds for both hospitalizations (aOR 1.89, 95% CI 1.65-2.18) and ED visits (aOR 2.59, 95% CI 2.18-3.07) (Tables 4a and 4b, respectively). Finally, living in a rural area decreased the odds of ED visits (aOR 0.32, 95% CI 0.21-0.47), but rural residence was not associated with hospitalizations in this adjusted multivariate model.

Since sex was revealed as an effect modifier for hospitalization and rurality was revealed as an effect modifier for ED visits, additional adjusted models were assessed stratifying by sex for hospitalizations and rurality for ED visits (Tables 4a and 4b, respectively). A fully adjusted logistic regression model on hospitalizations stratified by sex (Table 4a) showed that females with CHD and co-occurring MHD were more likely to have had any hospitalizations (aOR 4.63, 95% CI 4.01-5.34) compared to males with CHD and co-occurring MHD (aOR 3.21, 95% CI 2.72-3.79) (Table 4a). Additionally, males with valve defects were less likely to have experienced any hospitalizations (aOR 0.63, 95% CI 0.53-0.76); this finding was not found for females (Table 4a). Furthermore, females with severe CHD were more likely to have any hospitalizations (aOR 1.23, 95% CI 1.05-1.45) compared to females with other types of CHD, but this effect was not found among males (Table 4a).

When evaluating a fully adjusted logistic regression model on ED visits stratified by rurality (Table 4b), patients with CHD with co-occurring MHD who lived in urban areas were more likely to have had any ED visits (aOR 2.78, 95% CI 2.33-3.32) compared to those with CHD without co-occurring MHD; this finding was not seen for their counterparts living in rural areas. Additionally, patients with severe CHD living in urban areas were less likely to have any an ED visits (aOR 0.64, 95% CI 0.52-0.79), and those patients who were older, 30-54

years and living in rural areas were more likely to have had any ED visits (aOR 5.47, 95% CI 2.26-15.35) compared to their same aged counterparts residing in urban areas (aOR 2.62, 95% CI 2.18-3.15). Finally, non-Hispanic black patients with CHD and co-occurring MHD who lived in urban areas were at increased odds for any ED visits (aOR 2.69, 95% CI 2.25-3.22), and this finding was not present for those living in rural areas.

Adjusted multivariate analyses with the dichotomous severe and non-severe CHD variable included revealed that patients with co-occurring MHD had higher odds for both hospitalization (aOR 4.01, 95% CI 3.50-4.60) and ED visits (aOR 2.74, 95% CI 2.32-3.24) (Tables 5a and 5b, respectively). Patients with severe CHD were more likely to have had any hospitalizations (aOR 1.44, 95% CI 1.26-1.65) and less likely to have had any ED visits (aOR 0.69, 95% CI 0.57-0.84) (Tables 5a and 5b, respectively). Patients in the older 30-54-year-old age group had higher odds for both hospitalization (aOR 5.87, 95% CI 5.13-6.72 and ED visits (aOR 2.72, 95% CI 2.28-3.25) (Tables 5a and 5b, respectively). Females were at less likely to have had any hospitalizations (aOR 0.81, 95% CI 0.71-10.91), and there was no association of sex on ED visits in this multivariate model. Compared to non-Hispanic white patients, non-Hispanic black patients were at increased odds for both hospitalization (aOR 1.90, 95% CI 1.66-2.18) and ED visits (aOR 2.65, 95% CI 2.24-3.14) (Tables 5a and 5b, respectively). Finally, rurality decreased the odds of ED visits (aOR 0.32, 95% CI 0.21-0.46) (Table 5a), while rurality was not associated with hospitalizations.

As in the adjusted models with the 4-level CHD grouping applied, sex was revealed as an effect modifier for hospitalization and rurality was revealed as an effect modifier for ED visits when the dichotomous CHD variable was included. As such, additional adjusted models were assessed stratifying by sex for hospitalizations and rurality for ED visits (Tables 5a and

5b, respectively). Fully adjusted logistic regression stratified on sex (Table 5a) found that females with a MHD had higher odds for hospitalization (aOR 4.64, 95% CI 4.02-5.35) than males with a MHD (aOR 3.22, 95% CI 2.73-3.79). Both males with severe CHD (aOR 1.25, 95% CI 1.07 – 1.46) and females with severe CHD (aOR 1.28, 95% CI 1.11-1.48) were at increased odds for hospitalizations. When evaluating ED visits stratified by rurality (Table 5b), urban patients with a MHD had higher odds for an ED visit (aOR 2.85, 95% CI 2.40-3.37) compared to those without a MHD, but this effect was not found for rural patients. Additionally, urban patients with severe CHD had decreased odds of an ED visit (aOR 0.70, 95% CI 0.57-0.85) (Table 5b). Rural patients in the older 30-54-year-old age group had higher odds of an ED visit (aOR 5.52, 95% CI 2.29-15.48) compared to urban patients in the older age group (aOR 2.67, 95% CI 2.24-3.20) (Table 5b). Finally, non-Hispanic black patients living in urban areas had increased odds for an ED visit (aOR 2.69, 95% CI 2.27-3.19); this effect was not present for rural patients (Table 5b).

Adjusted multivariate logistic regression for hospitalizations and ED visits for patients with severe CHD classified as having conotruncal defects or not having conotruncal defects, both unstratified and stratified by their individual effect modifiers, were performed separately (Tables 6a and 6b). Unstratified multivariate logistic regressions revealed that patients with a MHD had higher odds for both hospitalization (aOR 3.92, 95% CI 3.06-5.03) and ED visits (aOR 2.70, 95% CI 1.91-3.79) (Tables 6a and 6b, respectively). Patients with conotruncal defects had higher odds for hospitalization (aOR 2.03, 95% CI 1.62-2.55) (Table 6a), but no similar effect was found for ED visits. Patients aged 30-54 years had higher odds for both hospitalization (aOR 5.30, 95% CI 4.20-6.71) and ED visits (aOR 1.84, 95% CI 1.32-2.59) (Tables 6a and 6b, respectively). Compared to non-Hispanic white patients, non-Hispanic

black patients were at increased odds for ED visits (aOR 2.63, 95% CI 1.86-3.74) (Table 6b), but not hospitalization. Finally, rurality decreased the odds of ED visits (OR 0.26, 95% CI 0.10-0.55) (Table 6b), but had no association with hospitalizations in this multivariate logic regression model.

Since sex was revealed as an effect modifier for hospitalization and race was revealed as an effect modifier for ED visits, additional adjusted models were assessed stratifying by sex for hospitalizations and race for ED visits (Tables 6a and bb, respectively). A fully adjusted logistic regression model for hospitalizations stratified by sex (Table 6a) found that females with co-occurring MHD were more likely to have had any hospitalizations (aOR 4.99, 95% CI 3.78-6.62) compared to their male counterparts (aOR 3.39, 95% CI 2.44-4.72) (Table 6a). Both males (aOR 2.23, 95% CI 1.68-2.98) and females (aOR 2.06, 95% CI 1.60-2.67) with conotruncal defects were at increased odds for hospitalization (Table 6a). Males in the 30-54-year-old age group were more likely to have had any hospitalizations (aOR 5.83, 95% CI 4.34-7.91) compared to their female counterparts of the same age (aOR 3.48, 95% CI 2.67-4.56) (Table 6a).

When evaluating ED visits stratified by race (Table 6b), Hispanic patients with co-occurring MHD were more likely to have had any ED visits (aOR 8.39, 95% CI 2.14-37.56) compared to non-Hispanic whites (aOR 2.28, 95% CI 1.43-3.63) or non-Hispanic black patients (aOR 2.83, 95% CI 1.69-4.68) (Table 6b). Non-Hispanic black patients in the older 30-54-year-old age group (aOR 1.68, 95% CI 1.05-2.74) and non-Hispanic white patients in the same age bracket (aOR 2.15, 95% CI 1.33-3.5) were more likely to have had any ED visits, but this finding was not revealed for older Hispanic patients in this stratified multivariate logistic model.

CHAPTER IV: DISCUSSION

The aim of this study was to evaluate the impact of MHD on hospitalizations and ED visits amongst patients with CHD. Overall, the results of this study support the study hypotheses that patients with CHD and co-occurring MHD have higher odds of both hospitalizations and ED visits compared to patients with CHD without co-occurring MHD. Additionally, results also support the hypothesis that severe CHD impacts this relationship. However, findings showed that while odds of hospitalizations were increased, severe disease actually lowered odds of ED visits. Therefore, while MHD appeared to play a significant role in this relationship, and CHD severity, age, sex, race and ethnicity, rurality, and insurance contributed to differential rates of hospitalizations and ED visits for those with CHD and co-occurring MHD. Fully adjusted logistic regression models found sex to be a significant effect modifier for hospitalizations, which is consistent with findings showing mental health disorders impact males and females differently.[40-43] Additionally, rurality and race were both effect modifiers for ED visits, which supports findings that suggest that blacks and Hispanic patients, as well as patients in rural areas have decreased access to care. [63-65, 68-70]

When evaluating the likelihood of hospitalizations, sex was an effect modifier across all three ways we categorized CHD severity. Female patients with CHD and co-occurring MHD were consistently more likely to have had any hospitalizations compared to male patients with CHD and co-occurring MHD. However, this sample includes female patients of child-bearing age and different types of hospitalizations were not differentiated. Therefore, having included female patients who may have been hospitalized due to pregnancy could potentially confound the relationship between sex and hospitalization. CHD anatomic group also had differing effects on males and females where males with valve disease were less likely to have

had any hospitalizations, while females with severe CHD were more likely to have had hospitalizations. However, once CHD was further collapsed into severe vs. non-severe and conotruncal vs. non-conotruncal defects, both males and females with severe CHD were more likely to have had any hospitalizations. This relationship could be clouded however, by the inclusion of pregnancy-related hospitalizations as females with severe CHD would likely have had more complicated pregnancies and deliveries requiring hospitalization. Complications related to contraception could also potentially affect hospitalization rates among females. Additionally, patients with conotruncal defects often require surgical revisions of the right ventricular outflow tract, pulmonary valve replacement, and occasionally, aortic/truncal valve replacement, and thus, they are more likely to require multiple surgical interventions which could contribute to this difference in hospitalizations. Those with conotruncal defects who have had a valve replacement are at higher risk for endocarditis which may further contribute to hospitalization rates. Finally, when evaluating CHD as conotruncal vs. non-conotruncal, age was an important factor for older patients who were more likely to have experienced hospitalizations, particularly for male patients. This is a reasonable finding as hospitalization was defined as any hospitalizations as opposed to a count of the number of hospitalizations, and older patients with CHD are more likely to be hospitalized at some point during their treatment history.[139-141] Future analyses should look at specific indications for hospitalizations to better understand sex and CHD-related differences in hospitalization rates.

When evaluating the likelihood of ED visits, rurality was a significant effect modifier when CHD was categorized into four anatomic groups as well as collapsed into severe vs. non-severe defects. Patients living in urban areas with a MHD also were more likely to visit the ED, but this finding was not revealed for those residing in rural areas. A potential explanation for

this finding could be lack of access to care as patients in rural areas have been reported to seek care less frequently, [63-65] which is potentially related to fewer healthcare facilities being located in rural areas or lack of resources needed to travel to healthcare facilities located in urban areas. Many factors contribute to the potential shortage of emergency medical services in rural areas such as increased closures of rural community hospitals, increased emergency medical services transport times, and high rural staff shortages.[142-146]

Additionally, urban patients with severe CHD were less likely to have any ED visits. While this may seem unexpected, patients with severe CHD often have more frequent scheduled outpatient medical office appointments as part of their routine care which could lead to earlier detection of health complications which lowers their need for emergency intervention. In a Canadian study based on population healthcare claims and diagnostic code data, 9% of adults and 12% of children had a severe CHD[19]. Contrastingly, 27% of the patients in this study had a severe CHD. This difference suggests that patients in the U.S. with severe CHD are more likely to be in care and thus, may be more likely to be admitted directly to the hospital when experiencing a complication, bypassing the ED. This effect was not found among rural patients with severe CHD which could be due to rural patients having to travel further for healthcare appointments and therefore, not attending as frequently. Similar to hospitalizations, both urban and rural patients in the older age group were more likely to have had ED visits. Finally, urban patients who were non-Hispanic black were more likely to visit the ED compared to non-Hispanic whites, and this finding was not revealed amongst rural patients with CHD. This finding provides additional support to the finding that black patients in the U.S. utilize ED services at higher rates than whites due to factors such as limited access to primary care services which leads to underutilization of preventative care.[147,148] Health

insurance coverage also likely impacts this relationship in the current study as some providers in Georgia do not accept Medicaid patients due to low reimbursement rates. Medicaid patients, which represent 76.8% of black patients in this study, may be of limited means and may not be able to afford travel costs or time off from work to seek healthcare. Furthermore, black patients who live in or were born in the south have been shown to be at especially high risk for ED visits.[149] In addition to rurality, race/ethnicity was an effect modifier when conotruncal vs. non-conotruncal defects were assessed among those patients with severe CHD. While the likelihood for having any ED visits among non-Hispanic white and non-Hispanic black patients with a MHD were similar, the odds were significantly higher among Hispanic patients with a MHD. Older non-Hispanic white and non-Hispanic black patients were also more likely to have had ED visits, but this effect was not found among Hispanic patients.

Data from this study suggest that patients with co-occurring CHD and MHD are more likely to have both hospitalizations and ED visits compared to those patients with CHD without MHD. Previous studies regarding the impacts of MHD supports these findings as patients with depressive disorders, anxiety disorders, and PTSD have been shown to have increased inpatient encounters and healthcare needs. [77-82] [111-114] The impacts of MHD are also often interrelated. For example, patients with PTSD have been shown to have more negative mental health consequences such as increased suicidality, lower psychosocial functioning, and an increased prevalence of mood and anxiety disorders. [33,117-121] The downstream consequences of concurrent MHD and chronic illness are incredibly complex and have a wide range of effects on patient well-being. Lower quality of life due physical symptoms can lead to depression, which, in turn, decreases adherence to treatment, which further contributes to quality-of-life deterioration.[150] Additionally, decreased treatment adherence is often associated

with worse prognosis, particularly for those with chronic illnesses where patient participation is a key factor for success such as when engaging in complex medication regimens or rehabilitation programs.[151] In a large study by Qian et al. (2013) with 17,320 Medicare patients, researchers found that among patients with chronic obstructive pulmonary disorder (COPD), depression was associated with increased mortality.[152] In study conducted by Montserrat et al. (2018) of 512 chronically-ill COPD patients, an increased risk of hospitalization was revealed among those with anxiety and depression disorders.[153] Similar results were reported by Maddigan et al. (2011) and Ose et al. (2005), who found that anxiety and depression among patients with chronic conditions resulted in particularly poor clinical outcomes such as increased risk of disability, hospitalization, and early mortality.[154,155]Findings from the current study, as well as data from previous research regarding MHD, CHD, and chronic illnesses suggests that further research should be conducted to determine how to optimize treatment and management for patients with co-occurring complex physical and psychological conditions. Patients with complex medical conditions and MHD will have a diverse set of needs requiring multidisciplinary collaboration. Delivering coordinated care will require integrating medical, psychiatric, primary care, and specialty services.

Limitations

There were several limitations of this study that should be addressed in future research. First, our analyses did not include non-specific or 'other' CHD diagnoses nor did it include 'other vascular' CHD conditions due to small cell size. Additionally, the analytic dataset included patients with an ICD-9-CM code of 745.5 in isolation or an ICD-10-CM code of Q21.1 in isolation. Previous studies of CHD have excluded these codes when not present in combination with at least one other specific diagnostic CHD-related code as these codes are

frequently not representative of a true CHD, particularly in older age groups. [10,14-16] Another limitation of the current study was the inability to include health insurance coverage data in the statistical models. Most patients in the current sample had public insurance sometime during the 10-year study period. Public health insurance was defined as ever having public health insurance coverage, and in Georgia, most children with CHD are covered under Medicaid until the age of 18. Additionally, pregnant women and adults over 19 who are disabled will also likely have Medicaid coverage. Finally, this study defined hospitalizations and ED visits as any occurrence in the 10-year study period as opposed to total number of hospitalizations or total number of ED visits, or annualized hospitalization and ED visit rates, which does not allow for a high degree of granularity. Reasons for hospitalizations and ED visits were also not differentiated or accounted for in the current analyses which could have contributed to the sex effect where pregnant females with increased hospitalizations and health care visits artificially inflated the likelihood of these healthcare utilization outcomes.

CHAPTER V: PUBLIC HEALTH IMPLICATIONS AND FUTURE DIRECTIONS

The results of this study have several public health implications, both for patients with CHD and for health care professionals who care for these patients. Our data suggests that not only are MHD prevalent among patients with CHD, but also that these co-occurring conditions contribute to significant health implications on the overall health and well-being of these patients which includes a greater likelihood for hospitalizations and ED visits. Providers should be mindful of their patients' mental health needs during regular appointments and help provide patients with CHD and co-occurring MHD the necessary resources. For example, if medical providers notice changes in a patient's mood or behavior, proper referrals should be made in a timely manner to a psychiatric professional to ensure that patients can access the treatments and medications they need. Additionally, an updated model for health care could be developed such that medical and psychiatric care services are more coordinated, with particular attention to depression and anxiety screening, which should be integrated into eHR as a preemptive screening tool. However, despite increased screening efforts, additional challenges remain due to the pervasive shortage of mental health providers in the U.S., and this is of particular concern in Georgia. Results from this study increases the urgency for public health and healthcare professionals to jointly address ongoing physician and psychotherapy provider shortages and gaps in healthcare insurance coverage. With Medicaid beneficiaries unlikely to be able to afford psychotherapy from out-of-network providers, many chronically ill patients with CHD and co-occurring MHD may not receive the specialized medical, psychiatric and psychotherapy treatments and care they need due to program and health care system shortcomings. Results from the current study support previous racial and ethnic disparities reported within the literature and suggest that racial and ethnic minorities with CHD and co-

occurring MHD are at increased risk for accessing the healthcare system through emergency departments.[147-149] Public health departments and healthcare providers should be aware of biases that exist within medicine and engage in trainings and education to help dispel these inequities in care. In particular, rural-urban disparities in ED utilization among patients with CHD and MHD needs further investigation. Reasons for disparities in healthcare utilization for patients with CHD and co-occurring MHD who live in rural locations compared to those residing in urban areas could be attributed to the underfunding and closures of smaller community hospitals in rural settings, which is a relevant public health policy challenge. Future studies looking at zip codes and healthcare facilities within zip codes could further elucidate this issue.

Future studies should be performed to gain more information regarding the impacts of MHD on CHD outcomes. Future studies could delve deeper into the relationship between MHD and CHD by separating MHD into individual diagnoses such as depressive disorders, anxiety disorders, PTSD, and schizophrenia. This could provide important information regarding which psychiatric disorders are most prevalent among patients with CHD, which psychiatric conditions lead to greater healthcare utilization and more complex morbidities, as well as increased mortality in this population.

Additionally, the relationship between CHD and psychotic disorders and schizophrenia warrants further exploration. More detailed information from eHRs could also be assessed regarding treatment history of MHD. For instance, for patients who have any psychiatric encounters, potential gaps in care could be evaluated and strategies to close such gaps could be identified and offered to psychiatric providers of chronically ill patients like those with CHD. Future studies could also include more detailed data on the types of hospitalizations and ED to

further tease out the impact that factors such as sex and rurality may have. Hospitalization and ED visit encounter data could also be captured in more detail, such as total number per year, annual rates over time, or age adjusted rates could be calculated and compared for those patients with CHD and co-occurring MHD. Also, as mentioned previously, further studies need to identify and separately analyze pregnancy-related hospitalizations and ED visits for females of child-bearing age with CHD and MHD.

The differences in hospitalization and ED visits revealed in the current study between patients with severe and non-severe CHD, with and without co-occurring MHD warrants further investigation to gain a deeper understanding behind the apparent protective effect of having a severe CHD. For example, including data on outpatient visits in addition to counts of hospitalizations and ED visits could reveal if increased frequency of outpatient care leads to reduced utilization of inpatient care. Finally, future studies should investigate the impact of additional socioeconomic factors such as income and education, as well as include more detailed information regarding insurance coverage, as these factors likely play a large roll in access and utilization of care, particularly for minority populations. Access to care could be further defined based on travel times to the closest medical facility, as well as quantified based on total number of healthcare facilities within specific zip codes.

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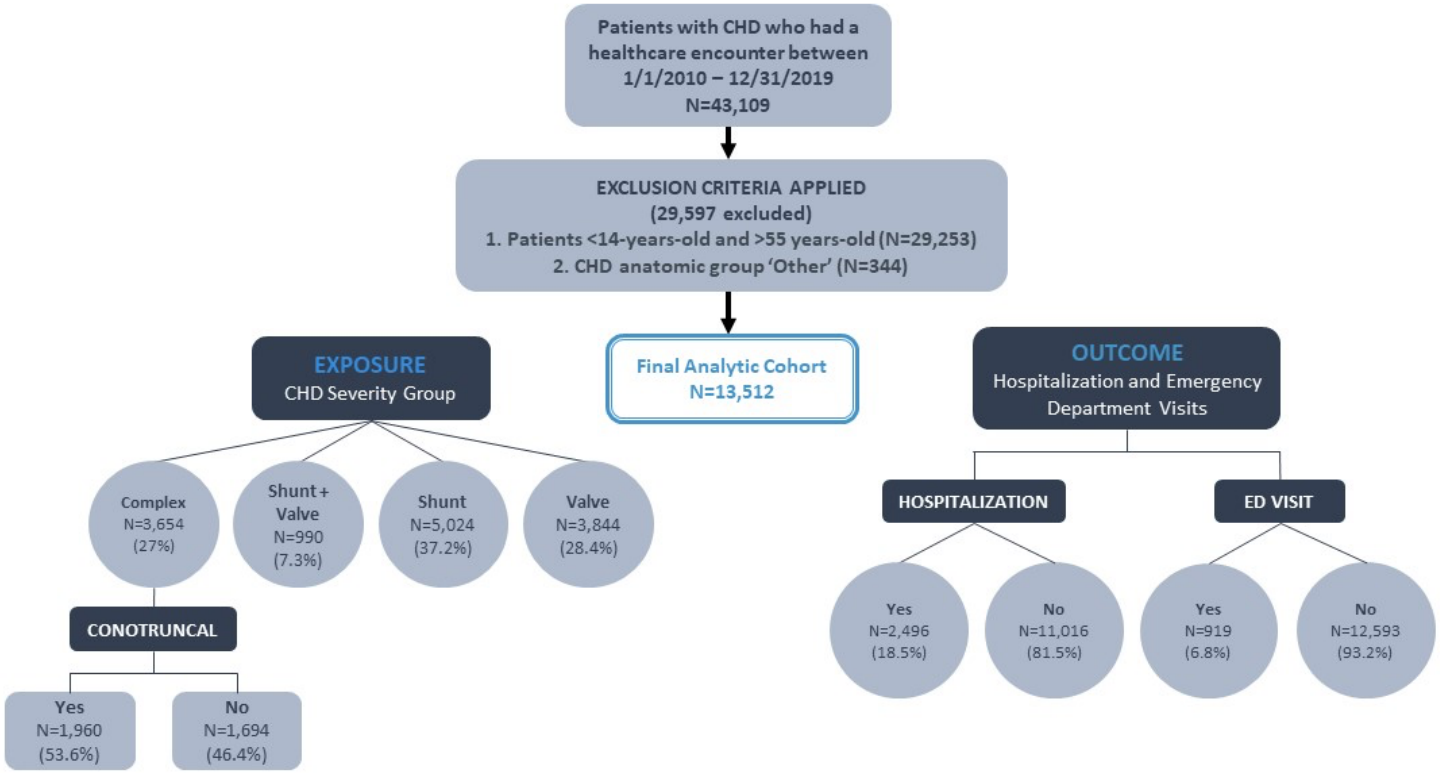
FIGURES

Figure 1: Analytic Dataset Construction



TABLES

Table 1. Descriptive Characteristics of Patients with Congenital Heart Defects (CHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta, 2010-2019

VARIABLES	N=13,512	%
OUTCOMES[1]		
Any Hospitalizations	2,496	18.47%
Any Emergency Department (ED) Visits	919	6.80%
EXPOSURE		
Any Mental Health Disorders (MHD)	2,757	20.40%
Depressive Disorders	938	6.94%
Anxiety Disorders	1,430	10.58%
Bipolar Disorders	159	1.18%
Post Traumatic Stress Disorders (PTSD)	578	4.28%
Personality Disorders	94	0.70%
Neurodevelopmental and Behavioral Disorders	851	6.30%
Psychotic Disorders and Schizophrenia	115	0.85%
COVARIATES		
CHD Anatomic Grouping (4 categories)		
Severe	3,654	27.04%
Shunt and Valve	990	7.33%
Shunt (Non-severe)	5,024	37.18%
Valve	3,844	28.45%
CHD Anatomic Grouping (2 categories)		
Non-severe	9,858	72.96%
Severe	3,654	27.04%
Conotruncal Defects[2] (Severe)	1,960	53.64%
Non-Conotruncal Defects	1,694	46.36%
Age Group (in years)[3]		
14-19	4,864	36.00%
20-29	3,875	28.68%
30-54	4,773	35.32%
Sex: Male	6,587	48.75%
Race and Ethnicity		
Non-Hispanic White	6,978	51.64%
Non-Hispanic Black	3,318	24.56%
Hispanic	833	6.16%
Other[4]	480	3.55%
Unknown	1,903	14.08%
Rurality[5]		
Rural	1,544	11.43%
Urban	10,929	80.88%
Unknown	1,039	7.69%
Insurance[6]		
Public	10,663	78.92%
Private	196	1.45%
Self-Pay	<10	--
Other	<10	--
Unknown	2,641	19.55%

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; ED=emergency department.

[1]Outcomes are not mutually exclusive.

[2]Conotruncal defects are a subet of severe CHD, and include: 1) Hypoplastic left heart syndrome (HLHS); 2) Common truncus; 3) Double outlet right ventricle (DOLV); 4) Tetralogy of Fallot (ToF); 5) Transposition of the great arteries (TGA); and 6) Interrupted aortic arch.

[3]Mean age is 27.05 years (SD 10.64).

[4]'Other' race/ethnicity includes American Indian/Alaskan Native, Asian, and Native Hawaiian/Pacific Islander, and

[5]Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro and micropolitan = urban; non-core and small metro = rural.

[6]The following classification hierarchy was applied for health insurance coverage over the 10-year study period: 1) any public insurance (i.e., Medicare, Medicaid, SCHIP, etc.); 2) private insurance only; 3) self-pay/uninsured; 4) other insurance; and 5) unknown.

Note. Cell sizes <10 are not reported.

Table 2. Bivariate Analyses: Distribution of Covariate Percentages on Hospitalizations and Emergency Department (ED) Visits for Patients with Congenital Heart Defects (CHD) and Co-occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta

		Any Hospitalizations					Any Emergency Department (ED) Visits					Any Mental Health Disorders (MHD)				
		No 81.53% (N=11,016)		Yes 18.47% (N=2,496)		X^2 p-value	No 93.20% (N=12,593)		Yes 6.80% (N=919)		X^2 p-value	MHD Not Present 79.60% (N=10,755)		MHD Present 20.40% (N=2,757)		X^2 p-value
Mental Health Disorders (MHD)	No	9,263	86.13%	1,492	13.87%	739.05, p<0.001	10,218	95.01%	537	4.99%	270.53 p<0.001					
	Yes	1,753	63.58%	1,004	36.42%		2,375	86.14%	382	13.86%						
CHD Anatomic Group (4 level)	Severe	2,848	77.94%	806	22.06%	56.71 p<0.001	3,446	94.31%	208	5.69%	40.98 p<0.001	2,801	76.66%	853	23.34%	42.59 p<0.001
	Shunt and Valve	812	82.02%	178	17.98%		936	94.55%	54	5.45%		791	79.90%	199	20.10%	
	Shunt	4,101	81.63%	923	18.37%		4,592	91.40%	432	8.60%		3,984	79.30%	1,040	20.70%	
	Valve	3,255	84.68%	589	15.32%		3,619	94.15%	225	5.85%		3,179	82.70%	665	17.30%	
CHD Anatomic Group (2 level)	Non-severe	8,168	82.86%	1,690	17.14%	42.43 <0.001	9,147	92.79%	711	7.21%	9.48 p=0.002	7,954	80.69%	1,904	19.31%	26.41 p<0.001
	Severe	2,848	77.94%	806	22.06%		3,446	94.31%	208	5.69%		2,801	76.66%	853	23.34%	
Conotruncal Defect[1]	No	9,577	82.90%	1,975	17.10%	99.47 p<0.001	10,744	93.01%	808	6.99%	4.48 p=0.034	9,296	80.47%	2,256	19.53%	37.17 p<0.001
	Yes	1,439	73.42%	521	26.58%		1,849	94.34%	111	5.66%		1,459	74.44%	501	25.56%	
Age Group (in years)	14-19	4,840	99.51%	24	0.49%	2660.02 p<0.001	4,842	99.55%	22	0.45%	671.96 p<0.001	4,004	82.32%	860	17.68%	93.58 p<0.001
	20-29	3,343	86.27%	532	13.73%		3,633	93.75%	242	6.25%		3,168	81.75%	707	18.25%	
	30-54	2,833	59.35%	1,940	40.65%		4,118	86.28%	655	13.72%		3,583	75.07%	1,190	24.93%	
Sex	Female	5,536	79.94%	1,389	20.06%	23.49 p<0.001	6,362	91.87%	563	8.13%	39.13 p<0.001	5,442	78.58%	1,483	21.42%	8.81 p=0.0029
	Male	5,480	83.19%	1,107	16.81%		6,231	94.60%	356	5.40%		5,313	80.66%	1,274	19.34%	
Race/Ethnicity	Non-Hispanic White	5,774	82.75%	1,204	17.25%	81.01 p<0.001	6,599	94.57%	379	5.43%	190.27 p<0.001	5,351	76.68%	1,627	23.32%	114.50 p<0.001
	Non-Hispanic Black	2,587	77.97%	731	22.03%		2,922	88.07%	396	11.93%		2,653	79.96%	665	20.04%	
	Hispanic	750	90.04%	83	9.96%		799	95.92%	34	4.08%		686	82.35%	147	17.65%	
	Other[2]	395	82.29%	85	17.71%		448	93.33%	32	6.67%		409	85.21%	71	14.79%	
	Unknown	1,510	79.35%	393	20.65%		1,825	95.90%	78	4.10%		1,656	87.02%	247	12.98%	
Rurality[3]	Rural	1,275	82.58%	269	17.42%	19.24 p<0.001	1,513	97.99%	31	2.01%	74.51 p<0.001	1,221	79.08%	323	20.92%	11.90 p=0.0026
	Urban	8,946	81.86%	1,983	18.14%		10,092	92.34%	837	7.66%		8,664	79.28%	2,265	20.72%	
	Unknown	795	76.52%	244	23.48%		988	95.09%	51	4.91%		870	83.73%	169	16.27%	
Insurance[4]	Any Public	8,261	77.47%	2,402	22.53%	176.04 p<0.001	9,785	91.77%	878	8.23%	55.85 p<0.001	8,443	79.18%	2,220	20.82%	3.71, p=.1561
	Private Only	196	100.00%	<10	--		194	100.00%	<10	--		163	83.16%	33	16.84%	
	Self-Pay/Uninsured	<10	--	<10	--		<10	--	<10	--		<10	--	<10	--	
	Other	<10	--	<10	--		<10	--	<10	--		<10	--	<10	--	
	Unknown	2,547	96.44%	94	3.56%		2,602	98.52%	39	1.48%		2,140	81.03%	501	18.97%	

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; ED=emergency department.

[1]Conotruncal defects are a subet of severe CHD, and include: 1) Hypoplastic left heart syndrome (HLLHS); 2) Common truncus; 3) Double outlet right ventricle (DOLV); 4) Tetralogy of Fallot (ToF); 5) Transposition of the great arteries (TGA); and 6) Interrupted aortic arch.

[2]'Other' race/ethnicity includes American Indian/Alaskan Native, Asian, and Native Hawaiian/Pacific Islander, and multi-racial.

[3]Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro and micropolitan = urban; non-core and small metro = rural.

[4]The following classification hierarchy was applied for health insurance coverage over the 10-year study period: 1) any public insurance (i.e., Medicare, Medicaid, SCHIP, etc.); 2) private insurance only; 3) self-pay/uninsured; 4) other insurance; and 5) unknown; X^2 analysis reflects any public, private only, and unknown as cell sizes for self-pay and other are either zero or too small.

Notes. Cell sizes <10 are not reported. Row percentages are reported.

Table 3. Unadjusted Analyses: Risk of Hospitalizations and Emergency Department (ED) Visits with Covariates for Patients with Congenital Heart Defects (CHD) and Co-occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta,

		Any Hospitalizations N = 8,648		Any Emergency Department (ED) Visits N = 8,648	
		cOR	**(95% CI)**	**cOR**	**(95% CI)**
Any Mental Health Disorders (MHD)	No	1.00	--	1.00	--
	Yes	**3.97**	**(3.57 – 4.42)**	**2.97**	**(2.57 – 3.43)**
CHD Anatomic Group (4 categories)	Severe	**1.13**	**(1.01 – 1.26)**	**0.53**	**(0.45 – 0.64)**
	Shunt and Valve	1.05	(0.87 – 1.28)	**0.64**	**(0.47 – 0.85)**
	Shunt	1.00	--	1.00	--
	Valve	**0.72**	**(0.64 – 0.81)**	**0.60**	**(0.50 – 0.71)**
CHD Anatomic Group (2 categories)	Non-Severe	1.00	--	1.00	--
	Severe	**1.27**	**(1.15 – 1.41)**	**0.67**	**(0.57 – 0.79)**
Conotruncal Defect[1]	No	1.00	--	1.00	--
	Yes	**1.75**	**(1.55 – 1.98)**	**0.71**	**(0.57 – 0.87)**
Age Group (in years)[2]	20-29	1.00	--	1.00	--
	30-54	**4.30**	**(3.86 – 4.80)**	**2.39**	**(2.05 – 2.79)**
Sex	Male	1.00	--	1.00	--
	Female	1.07	(0.98 – 1.18)	**1.37**	**(1.19 – 1.58)**
Race/Ethnicity	Non-Hispanic White	1.00	--	1.00	--
	Non-Hispanic Black	**1.54**	**(1.37 – 1.72)**	**2.67**	**(2.29 – 3.11)**
	Hispanic	0.85	(0.65 – 1.09)	1.16	(0.78 – 1.66)
Rurality[2]	Urban	1.00	--	1.00	--
	Rural	1.07	(0.91 – 1.24)	**0.27**	**(0.18 – 0.38)**

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; ED=emergency department; cOR=crude odds ratio.

[1]Conotruncal defects are a subet of severe CHD, and include: 1) Hypoplastic left heart syndrome (HLLHS); 2) Common truncus; 3) Double outlet right ventricle (DOLV); 4) Tetralogy of Fallot (ToF); 5) Transposition of the great arteries (TGA); and 6) Interrupted aortic arch.

[2]Age group 14-19 was removed due to insufficient sample size.

[3]Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro and micropolitan = urban; non-core and small metro = rural.

Notes. 95% CI are in parentheses. Significant analyses are in bold. Total N reflects removal of 14-19 year-old age group.

Table 4a. Adjusted Analyses: Risk of Hospitalizations for Select Covariates for Patients with Congenital Heart Defects (CHD) and Co-Occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta

		Any Hospitalizations (N=5,991)		Any Hospitalizations Males (N = 3,940)		Females (N = 4,708)	
		aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)
Any Mental Health Disorders (MHD)	No	1.00	--	1.00	--	1.00	--
	Yes	**4.01**	**(3.50 – 4.60)**	**3.21**	**(2.72 – 3.79)**	**4.63**	**(4.01 – 5.34)**
CHD Anatomic Group (4 categories)	Severe	**1.45**	**(1.24 – 1.69)**	1.02	(0.85 – 1.22)	**1.23**	**(1.05 – 1.45)**
	Shunt and Valve	1.27	(0.98 – 1.65)	1.14	(0.84 – 1.54)	1.07	(0.81 – 1.40)
	Shunt	1.00	--	1.00	--	1.00	--
	Valve	0.96	(0.81 – 1.13)	**0.63**	**(0.53 – 0.76)**	0.88	(0.73 – 1.05)
Age Group (in years)[1]	20-29	1.00	--				
	30-54	**5.87**	**(5.14 – 6.73)**				
Sex	Male	1.00	--				
	Female	**0.80**	**(0.70 – 0.91)**				
Race	Non-Hispanic White	1.00	--				
	Non-Hispanic Black	**1.89**	**(1.65 – 2.18)**				
	Hispanic	1.32	(0.97 – 1.78)				
Rurality[2]	Urban	1.00	--				
	Rural	1.19	(0.97 – 1.44)				

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; aOR=adjusted odds ratio.

[1]Age group 14-19 was removed due to insufficient sample size.

[2] Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro and micropolitan = urban; non-core and small metro = rural.

Notes. 95% CI are in parentheses. Significant analyses are in bold.

Table 4b. Adjusted Analyses: Risk of Emergency Department (ED) Visits for Select Covariates for Patients with Congenital Heart Defects (CHD) and Co-Occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta

		Any Emergency Department (ED) Visits (N=5,991)		Any Emergency Department (ED) Visits Urban (N = 4,934)		Rural (N = 665)	
		aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)
Mental Health Disorders (MHD)	No	1.00	--	1.00	--	1.00	--
	Yes	**2.73**	**(2.30 – 3.22)**	**2.78**	**(2.33 – 3.32)**	1.44	(0.61 – 3.26)
CHD Anatomic Group (4 categories)	Severe	**0.63**	**(0.51 – 0.78)**	**0.64**	**(0.52 – 0.79)**	0.52	(0.17 – 1.47)
	Shunt and Valve[1]	**0.66**	**(0.45 – 0.94)**	--	--	--	--
	Shunt	1.00	--	1.00	--	1.00	--
	Valve	0.85	(0.69 – 1.05)	0.83	(0.67 – 1.03)	1.09	(0.43 – 2.77)
Age Group (in years)[2]	20-29	1.00	--	1.00	--	1.00	--
	30-54	**2.68**	**(2.25 – 3.21)**	**2.62**	**(2.18 – 3.15)**	**5.47**	**(2.26 – 15.35)**
Sex	Male	1.00	--				
	Female	1.09	(0.93 – 1.29)				
Race	Non-Hispanic White	1.00	--	1.00	--	1.00	--
	Non-Hispanic Black	**2.59**	**(2.18 – 3.07)**	**2.69**	**(2.25 – 3.22)**	2.27	(0.85 – 5.65)
	Hispanic	1.41	(0.93 – 2.08)	1.51	(0.98 – 2.26)	3.12	(0.16 – 19.55)
Rurality[3]	Urban	1.00	--				
	Rural	**0.32**	**(0.21 – 0.47)**				

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; ED=emergency department; aOR=adjusted odds ratio.

[1]Shunt and valve was removed from final the stratified urban/rural model due to insufficient sample size.

[2]Age group 14-19 was removed due to insufficient sample size.

[3]Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro and micropolitan = urban; non-core and small metro = rural.

Notes. 95% CI are in parentheses. Significant analyses are in bold.

Table 5a. Adjusted Analyses: Risk of Hospitalizations for Select Covariates for Patients with Severe vs. Non-Severe Congenital Heart Defects (CHD) and Co-Occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta

		Any Hospitalizations (N=5,991)		Any Hospitalizations Males (N = 3,940)		Any Hospitalizations Females (N = 4,708)	
		aOR (95% CI)		aOR (95% CI)		aOR (95% CI)	
Mental Health Disorders (MHD)	No	1.00	--	1.00	--	1.00	--
	Yes	**4.01**	**(3.50 – 4.60)**	**3.22**	**2.73 – 3.79**	**4.64**	**4.02 – 5.35**
CHD Anatomic Group (2 categories)	Non-Severe	1.00	--	1.00	--	1.00	--
	Severe	**1.44**	**(1.26 – 1.65)**	**1.25**	**1.07 – 1.46**	**1.28**	**1.11 – 1.48**
Age Group (in years)[1]	20-29	1.00	--				
	30-54	**5.87**	**(5.13 – 6.72)**				
Sex	Male	1.00	--				
	Female	**0.81**	**(0.71 – 0.91)**				
Race	Non-Hispanic White	1.00	--				
	Non-Hispanic Black	**1.90**	**(1.66 – 2.18)**				
	Hispanic	1.34	(0.99 – 1.80)				
Rurality[2]	Urban	1.00	--				
	Rural	1.18	(0.97 – 1.44)				

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; aOR=adjusted odds ratio.

[1]Age group 14-19 was removed due to insufficient sample size.

[2] Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro

Notes. 95% CI are in parentheses. Significant analyses are in bold.

Table 5b. Adjusted Analyses: Risk of Emergency Department (ED) Visits for Select Covariates for Patients with Severe vs. Non-Severe Congenital Heart Defects (CHD) and Co-Occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta

		Any Emergency Department (ED) Visits (N=5,991)		Any Emergency Department (ED) Visits Urban (N = 5,288)		Any Emergency Department (ED) Visits Rural (N = 703)	
		aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)
Mental Health Disorders (MHD)	No	1.00	--	1.00	--	1.00	--
	Yes	**2.74**	**(2.32 – 3.24)**	**2.85**	**(2.40 – 3.37**	1.39	(0.59 – 3.14)
CHD Anatomic Group (2 categories)	Non-Severe	1.00	--	1.00	--	1.00	--
	Severe	**0.69**	**(0.57 – 0.84)**	**0.70**	**(0.57 – 0.85)**	0.55	(0.20 – 1.32)
Age Group (in years)[1]	20-29	1.00	--	1.00	--	1.00	--
	30-54	**2.72**	**(2.28 – 3.25)**	**2.67**	**(2.24 – 3.20)**	**5.52**	**(2.29 – 15.48)**
Sex	Male	1.00	--				
	Female	1.11	(0.94 – 1.31)				
Race	Non-Hispanic White	1.00	--	1.00	--	1.00	--
	Non-Hispanic Black	**2.65**	**(2.24 – 3.14)**	**2.69**	**(2.27 – 3.19)**	2.38	(0.93 – 5.66)
	Hispanic	1.42	(0.93 – 2.09)	1.39	(0.91 – 2.06)	3.35	(0.17 – 20.83)
Rurality[2]	Urban	1.00	--				
	Rural	**0.32**	**(0.21 – 0.46)**				

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; ED=emergency department; aOR=adjusted odds ratio.

[1]Age group 14-19 was removed due to insufficient sample size.

[2] Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro and micropolitan = urban; non-core and small metro = rural.

Notes. 95% CI are in parentheses. Significant analyses are in bold.

Table 6a. Adjusted Analyses: Risk of Hospitalizations for Select Covariates for Patients with Conotruncal vs. Non-Conotruncal Congenital Heart Defects (CHD) and Co-Occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta

		Any Hospitalizations (N=1,748)		Any Hospitalizations Males (N = 1,125)		Any Hospitalizations Females (N = 1,354)	
		aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)
Mental Health Disorders (MHD)	No	1.00	--	1.00	--	1.00	--
	Yes	**3.92**	**(3.06 – 5.03)**	**3.39**	**(2.44 – 4.72)**	**4.99**	**(3.78 – 6.62)**
Conotruncal Defect[1]	No	1.00	--	1.00	--	1.00	--
	Yes	**2.03**	**(1.62 – 2.55)**	**2.23**	**(1.68 – 2.98)**	**2.06**	**(1.60 – 2.67)**
Age Group (in years)[2]	20-29	1.00	--	1.00	--	1.00	--
	30-54	**5.30**	**(4.20 – 6.71)**	**5.83**	**(4.34 – 7.91)**	**3.48**	**(2.67 – 4.56)**
Sex	Male	1.00	--				
	Female	0.90	(0.72 – 1.13)				
Race	Non-Hispanic White	1.00	--				
	Non-Hispanic Black	1.27	(0.99 – 1.63)				
	Hispanic	0.82	(0.47 – 1.39)				
Rurality[3]	Urban	1.00	--				
	Rural	1.09	(0.79 – 1.50)				

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; aOR=adjusted odds ratio.

[1]Conotruncal defects are a subet of severe CHD, and include: 1) Hypoplastic left heart syndrome (HLHS); 2) Common truncus; 3) Double outlet right ventricle (DOLV); 4) Tetralogy of Fallot (ToF); 5) Transposition of the great arteries (TGA); and 6) Interrupted aortic arch.

[2]Age group 14-19 was removed due to insufficient sample size.

[3]Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro,

Notes. 95% CI are in parentheses. Significant analyses are in bold.

Table 6b. Adjusted Analyses: Risk of Emergency Department (ED) Visits for Select Covariates for Patients with Conotruncal vs. Non-Conotruncal Congenital Heart Defects (CHD) and Co-Occurring Mental Health Disorders (MHD) who have received care at Emory Healthcare and/or Children's Healthcare of Atlanta

		Any Emergency Department (ED) Visits (N=1,748)		Any Emergency Department (ED) Visits White (N = 1,214)		Black (N = 576)		Hispanic (N = 103)	
		aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)
Mental Health Disorders (MHD)	No	1.00	--	1.00	--	1.00	--	1.00	--
	Yes	**2.70**	**(1.91 – 3.79)**	**2.28**	**(1.43 – 3.63)**	**2.83**	**(1.69 – 4.68)**	**8.39**	**(2.14 – 37.56)**
Conotruncal Defect[1]	No	1.00	--	1.00	--	1.00	--	1.00	--
	Yes	0.92	(0.66 – 1.29)	0.74	(0.46 – 1.17)	1.08	(0.67 – 1.77)	1.87	(0.44 – 9.95)
Age Group (in years)[2]	20-29	1.00	--	1.00	--	1.00	--	1.00	--
	30-54	**1.84**	**(1.32 – 2.59)**	**1.68**	**(1.05 – 2.74)**	**2.15**	**(1.33 – 3.50)**	0.94	(0.18 – 4.21)
Sex	Male	1.00	--	1.00	--	1.00	--	1.00	--
	Female	1.19	(0.85 – 1.68)	1.08	(0.68 – 1.73)	1.12	(0.69 – 1.87)	4.08	(0.89 – 29.71)
Race	Non-Hispanic White	1.00	--						
	Non-Hispanic Black	**2.63**	**(1.86 – 3.74)**						
	Hispanic	1.92	(0.89 – 3.78)						
Rurality[3]	Urban	1.00	--						
	Rural	**0.26**	**(0.10 – 0.55)**						

Abbreviations: CHD=congenital heart defects; MHD=mental health disorders; ED=emergency department; aOR=adjusted odds ratio.

[1]Conotruncal defects are a subet of severe CHD, and include: 1) Hypoplastic left heart syndrome (HLHS); 2) Common truncus; 3) Double outlet right ventricle (DOLV); 4) Tetralogy of Fallot (ToF); 5) Transposition of the great arteries (TGA); and 6) Interrupted aortic arch.

[2]Age group 14-19 was removed due to insufficient sample size.

[3]Rurality defined using National Center for Health Statistics (NCHS) classification: large central metro, large fringe metro, medium metro and micropolitan = urban; non-core and small metro = rural.

Notes. 95% CI are in parentheses. Significant analyses are in bold.

APPENDICES

APPENDIX A: CHD Severity Group Assignment

Severity Group Classification	ICD-9-CM	ICD-10-CM	Primary Diagnosis
SEVERE (1)	***Case has a Severe code, regardless of presence of Shunt, Valve, or 'Other' Group codes.***		
			HLHS
	746.7	Q23.4	Hypoplastic left heart syndrome
			Tricuspid atresia
	746.1	Q22.4	Tricuspid atresia, stenosis or absence
		Q22.6	Hypoplastic right heart syndrome
			Single ventricle defects, except HLHS
	745.3	Q20.4	Single Ventricle, or cor triloculare (DILV, double inlet LV, double inlet left ventricle, diagnosis with 'Fontan')
	745.7		Cor biloculare (previously in 'other')
			Pulmonary atresia-heterogenous group, VSD v. IVS
	746.01	Q22.0	Pulmonary valve atresia or absence
			Truncus Arteriosus
	745.0	Q20.0	Common Truncus
			DOV (Double outlet ventricle)
	745.11	Q20.1	DORV (Double outlet right ventricle
		Q20.2	DOLV (Double outlet Left Ventricle)
			TOF
	745.2	Q21.3	Tetralogy of Fallot (TOF, tet)
			dTGA
	745.1	Q20.3	Transposition of the Great Arteries (TGA), Complete TGA (dextro-TGA), NOS or classical (dTGA, TGA)
	745.10		TGA
	745.19		TGA OS (dTGA, transposition of the great arteries)
			CCTGA (LTGA)
	745.12	Q20.5	Corrected TGA (levo-TGA) [congenitally corrected transposition of the great arteries, CCTGA, LTGA]
			CAVC defects
	745.6	Q21.2	Endocardial Cushion Defect (aka AVSD) [CAVCD, complete AV canal, atrioventricular canal]
	745.60		Endocardial Cushion Defect (aka AVSD) unspecified
	745.69		Endocardial Cushion Defect, Other

			Interupted arch
	747.11	Q25.21	Interrupted aortic arch
			TAPVR
	747.41	Q26.2	Total anomalous pulmonary venous return (TAPVR)
SHUNT AND VALVE (2)	***Case has NO SEVERE code. Case has both a Shunt code (group 3) <u>AND</u> a Valve code (group 4); case may also have 'Other' group codes***		
SHUNT (3)	***Case has ONLY SHUNT codes, AND has NO CODES in SEVERE or VALVE***		
			VSD, ventricular septal defect
	745.4	Q21.0	VSD, ventricular septal defect
			Secundum ASD, also includes PFO
	745.5	Q21.1	ASD2 or PFO, secundum atrial septal defect, EXCLUDES patent formen ovale
			Primum ASD
	745.61	None	ASD-1 (primum atrial septal defect)
			Non-specific septal defect-EXCLUDE PFO, sinus venosus, etc.
	745.8	Q21.8	Other specified defect of septal closure, sinus venosus atrial septal defect, inferior, superior
		Q21.9	Congenital malformation of cardiac septum, unspecified
	745.9		Unspecified defect of septal closure
			PDA, patent ductus arteriosus
	747.0	Q25.0	PDA, patent ductus arteriosus (at least one encounter at 3 months of age or older with PDA code)
			AP Window
	None	Q21.4	Aortopulmonary septal defect
			PAPVR
	747.42	Q26.3	Partial anomalous venous return (PAPVR)
		Q26.4	Anomalous pulmonary venous connection, unspecified
VALVE (4)	***Case has ONLY VALVE codes, AND has NO CODES in Severe or Shunt***		
			Pulmonary valve stenosis and/or regurgitation
	746.0		Anomalies of pulmonary valve
	746.00	Q22.3	Pulmonary valve anomaly, unspecified
	746.02	Q22.1	Pulmonary valve stenosis, PS

	746.09	Q22.2	Pulmonary valve anomaly, other, pulmonary regurgitation
			Congenital Tricuspid Valve Abnormalities
	746.2	Q22.5	Ebstein Anomaly (of tricuspid valve)
		Q22.8	Other congenital malformations of tricuspid valve
		Q22.9	Congenital malformation of tricuspid valve, unspecified
			Aortic stenosis, regurgitation and/or BAV
	746.3	Q23.0	Aortic valve stenosis (AS)
	746.4	Q23.1	Aortic insufficiency or bicuspid/unicuspid aortic vavle (AI, AR)
			Other left sided Valve anomalies (mixed aortic/mitral)
		Q23.8	Other congenital malformations of aortic and mitral valves
		Q23.9	Congenital malformation of aortic and mitral valves, unspecified
			Congenital mitral stenosis and/or regurgitation
	746.5	Q23.2	Mitral stenosis or mitral valve abnormalities (MS)
	746.6	Q23.3	Mitral insufficiency (MR), cleft mitral valve, MVP
			Subaortic stenosis, excluding HCM
	746.81	Q24.4	Subaortic stenosis, SubAS, Subaortic membrane, LVOT obstruction
			SubPS
	746.83	Q24.3	Infundibular or subvalvar pulmonary stenosis (sub PS))
			Coarctation of aorta (COA)
	747.10 or 747.1	Q25.1	Coarctation of aorta (COA)
			Other aortic anomalies
		Q25.3	Supravalvular aortic stenosis
		Q25.42	Hypoplasia of aorta
	747.22	Q25.29	Atresia or stenosis of aorta
		Q25.41	Absence and aplasia of aorta
			Abnormalities of branch pulmonary arteries
		Q25.5	Atresia of pulmonary artery

	747.31	Q25.71	Pulmonary artery atresia, coarctation, or hypoplasia (Branch), atresia of LPA, RPA
	747.39	Q25.79	Anomalies of Pulmonary artery, other

APPENDIX B: ICD-9-CM and ICD-10-CM Codes for Seven Mental Health Disorders

CLASSIFICATION	ICD-9-CM CODE	ICD-10-CM CODE	ICD-10-CM CODE DESCRIPTION
Depressive Disorders **54 codes** **(25 ICD-9-CM codes)** **(29 ICD-10-CM codes)**	29383	F0630	Mood disorder due to known physiological condition, unspec.
	29383	F0631	Mood disorder due to known physiological condition with depressive features
	29383	F0632	Mood disorder due to known physiological condition with major depressive-like episode
	29383	F0633	Mood disorder due to known physiological condition with manic features
	29383	F0634	Mood disorder due to known physiological condition with mixed features
	29383	F0634	Mood disorder due to known physiological condition with mixed features
	29621	F320	Major depressive disorder, single episode, mild
	29622	F321	Major depressive disorder, single episode, moderate
	29623	F322	Major depressive disorder, single episode, severe without psychotic features
	29624, 2980	F323	Major depressive disorder, single episode, severe with psychotic features
	29625	F324	Major depressive disorder, single episode, in partial remission
	29626	F325	Major depressive disorder, single episode, in full remission
	29682	F328	Other depressive episodes
	29682	F3289	Other specified depressive episodes
	29620, 311	F329	Major depressive disorder, single episode, unspec.
	29631	F330	Major depressive disorder, recurrent, mild
	29632	F331	Major depressive disorder, recurrent, moderate
	29633	F332	Major depressive disorder, recurrent severe without psychotic features
	29634, 2980	F333	Major depressive disorder, recurrent, severe with psychotic symptoms
	29630	F3340	Major depressive disorder, recurrent, in remission, unspec.
	29635	F3341	Major depressive disorder, recurrent, in partial remission
	29636	F3342	Major depressive disorder, recurrent, in full remission
	29699	F338	Other recurrent depressive disorders
	29630	F339	Major depressive disorder, recurrent, unspec.
	30112, 3004	F341	Dysthymic disorder
Anxiety Disorders	29384	F064	Anxiety disorder due to known physiological condition
	30022	F4000	Agoraphobia, unspecified

26 codes (13 ICD-9-CM codes) (13 ICD-10-CM codes)	30021	F4001	Agoraphobia with panic disorder
	30022	F4002	Agoraphobia without panic disorder
	30023	F4010	Social phobia, unspecified
	30023	F4011	Social phobia, generalized
	30001	F410	Panic disorder [episodic paroxysmal anxiety]
	30002	F411	Generalized anxiety disorder
	30009	F413	Other mixed anxiety disorders
	30009	F418	Other specified anxiety disorders
	30000	F419	Anxiety disorder, unspecified
	30921	F930	Separation anxiety disorder of childhood
	31323	F940	Selective mutism
Bipolar Disorders **77 codes (38 ICD-9-CM codes) (39 ICD-10-CM codes)**	30110, 30113	F340	Cyclothymic disorder
	29600	F3010	Manic episode without psychotic symptoms, unspecified
	29601	F3011	Manic episode without psychotic symptoms, mild
	29602	F3012	Manic episode without psychotic symptoms, moderate
	29603	F3013	Manic episode, severe, without psychotic symptoms
	29604	F302	Manic episode, severe with psychotic symptoms
	29605	F303	Manic episode in partial remission
	29606	F304	Manic episode in full remission
	29681	F308	Other manic episodes
	29600	F309	Manic episode, unspec.
	29640	F310	Bipolar disorder, current episode hypomanic
	29640	F3110	Bipolar disorder, current episode manic without psychotic features, unspec.
	29641	F3111	Bipolar disorder, current episode manic without psychotic features, mild
	29642	F3112	Bipolar disorder, current episode manic without psychotic features, moderate
	29643	F3113	Bipolar disorder, current episode manic without psychotic features, severe
	29644	F312	Bipolar disorder, current episode manic severe with psychotic features
	29650	F3130	Bipolar disorder, current episode depressed, mild or moderate severity, unspec.
	29651	F3131	Bipolar disorder, current episode depressed, mild
	29652	F3132	Bipolar disorder, current episode depressed, moderate
	29653	F314	Bipolar disorder, current episode depressed, severe, without psychotic features
	29654	F315	Bipolar disorder, current episode depressed, severe, with psychotic features

	29660	F3160	Bipolar disorder, current episode mixed, unspecified
	29661	F3161	Bipolar disorder, current episode mixed, mild
	29662	F3162	Bipolar disorder, current episode mixed, moderate
	29663	F3163	Bipolar disorder, current episode mixed, severe, without psychotic features
	29664	F3164	Bipolar disorder, current episode mixed, severe, with psychotic features
	2967	F3170	Bipolar disorder, currently in remission, most recent episode unspec.
	2967	F3171	Bipolar disorder, in partial remission, most recent episode hypomanic
	2967	F3172	Bipolar disorder, in full remission, most recent episode hypomanic
	29645	F3173	Bipolar disorder, in partial remission, most recent episode manic
	29646	F3174	Bipolar disorder, in full remission, most recent episode manic
	29655	F3175	Bipolar disorder, in partial remission, most recent episode depressed
	29656	F3176	Bipolar disorder, in full remission, most recent episode depressed
	29665	F3177	Bipolar disorder, in partial remission, most recent episode mixed
	29666	F3178	Bipolar disorder, in full remission, most recent episode mixed
	29689	F3181	Bipolar II disorder
	29640	F3189	Other bipolar disorder
	29680	F319	Bipolar disorder, unspec.
Post-Traumatic Stress Disorder (PTSD) **85 codes (41 ICD-9-CM codes) (44 ICD-10-CM codes)**	3089	F430	Acute stress reaction
	30981	F4310	Post-traumatic stress disorder, unspec.
	30981	F4311	Post-traumatic stress disorder, acute
	30981	F4312	Post-traumatic stress disorder, chronic
	3099	F4320	Adjustment disorder, unspec.
	3090, 3091	F4321	Adjustment disorder with depressed mood
	30924	F4322	Adjustment disorder with anxiety
	30928	F4323	Adjustment disorder with mixed anxiety and depressed mood
	3093	F4324	Adjustment disorder with disturbance of conduct
	3094	F4325	Adjustment disorder with mixed disturbance of emotions and conduct
	30929	F4329	Adjustment disorder with other symptoms
	30989	F438	Other reactions to severe stress
	3099	F439	Reaction to severe stress, unspec.
	30012	F440	Dissociative amnesia

	30013	F441	Dissociative fugue
	30019	F442	Dissociative stupor
	30011	F444	Conversion disorder with motor symptom or deficit
	30011	F445	Conversion disorder with seizures or convulsions
	30011	F446	Conversion disorder with sensory symptom or deficit
	30011	F447	Conversion disorder with mixed symptom presentation
	30014	F4481	Dissociative identity disorder
	30016, 2982	F4489	Other dissociative and conversion disorders
	30015	F449	Dissociative and conversion disorder, unspec.
	3006	F481	Depersonalization-derealization syndrome
	31389	F941	Reactive attachment disorder of childhood
	31389	F942	Disinhibited attachment disorder of childhood
	30081	F450	Somatization disorder
	30082	F451	Undifferentiated somatoform disorder
	30082, 3069	F459	Somatoform disorder, unspec.
	30089	F458	Other somatoform disorders
	3060	F458	
	3061	F458	
	3062	F458	
	3063	F458	
	3064	F458	
	30650	F458	
	30652	F458	
	30653	F458	
	30659	F458	
	3067	F458	
	3068	F458	
Personality Disorders **32 codes (14 ICD-9-CM codes) (18 ICD-10-CM codes)**	3100, 3101	F070	Personality change due to known physiological condition
	3010	F600	Paranoid personality disorder
	30120	F601	Schizoid personality disorder
	3017	F602	Antisocial personality disorder
	3013, 30183	F603	Borderline personality disorder
	30150, 30159	F604	Histrionic personality disorder
	3014	F605	Obsessive-compulsive personality disorder
	30182	F606	Avoidant personality disorder
	3016	F607	Dependent personality disorder
	30181	F6081	Narcissistic personality disorder
	30184, 30189	F6089	Other specific personality disorders
	3019	F609	Personality disorder, unspec.

	3019	F69	Unspecified disorder of adult personality and behavior
	3003	F42	Obsessive-compulsive disorder
Neurodevelopmental and Behavior Disorders **53 codes (23 ICD-9-CM codes) (30 ICD-10-CM codes)**	31401	F902	Attention-deficit hyperactivity disorder, combined type
	31401, 3142	F908	Attention-deficit hyperactivity disorder, other type
	31400, 31401	F909	Attention-deficit hyperactivity disorder, unspec.
	30929, 3139	F948	Other childhood disorders of social functioning
	31389	F949	Childhood disorder of social functioning, unspec.
	30721	F950	Transient tic disorder
	30722	F951	Chronic motor or vocal tic disorder
	30723	F952	Tourette syndrome disorder
	30720	F958	Other tic disorders
	30720	F959	Tic disorder, unspec.
	3073	F984	Stereotyped movement disorders
	3070	F985	Adult-onset fluency disorder
	31389	F988	Other specified behavioral and emotional disorders with onset usually occurring in childhood and adolescence
	31234, 31235	F6381	Intermittent explosive disorder
	31239	F6389	Other impulse disorders
	31230	F639	Impulse disorder, unspec.
	3017	F602	Antisocial personality disorder
	31289	F910	Conduct disorder confined to family context
	31200, 31281	F911	Conduct disorder, childhood-onset type
	31220, 31282	F912	Conduct disorder, adolescent-onset type
	31381	F913	Oppositional defiant disorder
	31210, 31289	F918	Other conduct disorders
	3129	F919	Conduct disorder, unspec.
Psychotic Disorders and Schizophrenia **47 codes (21 ICD-9-CM codes) (26 ICD-10-CM codes)**	29382	F060	Psychotic disorder with hallucinations due to known physiological condition
	29389, 2948	F061	Catatonic disorder due to known physiological condition
	29381	F062	Psychotic disorder with delusions due to known physiological condition
	29530	F200	Paranoid schizophrenia
	29510	F201	Disorganized schizophrenia
	29520	F202	Catatonic schizophrenia
	29590	F203	Undifferentiated schizophrenia
	29560	F205	Residual schizophrenia
	29540	F2081	Schizophreniform disorder
	29580	F2089	Other schizophrenia
	29590	F209	Schizophrenia, unspec.
	30122	F21	Schizotypal disorder

	2970, 2971, 2972	F22	Delusional disorders
	2983, 2984, 2988	F23	Brief psychotic disorder
	2973	F24	Shared psychotic disorder
	29570	F250	Schizoaffective disorder, bipolar type
	29570	F251	Schizoaffective disorder, depressive type
	29570	F258	Other schizoaffective disorders
	29570	F259	Schizoaffective disorder, unspec.
	2989	F28	Other psychotic disorder not due to a substance or known physiological condition
	2989	F29	Unspecified psychosis not due to a substance or known physiological condition

APPENDIX C: ICD-9-CM and ICD-10-CM Codes for Conotruncal Defects

	ICD-9-CM	ICD-10-CM	Diagnosis Description
CONOTRUNCAL DEFECTS **14 codes (8 ICD-9-CM codes) (6 ICD-10-CM codes)**			**HLHS**
	746.7	Q23.4	Hypoplastic left heart syndrome
			Truncus Arteriosus
	745.0	Q20.0	Common Truncus
			DOV (Double outlet ventricle)
	745.11	Q20.1	DORV (Double Outlet Right Ventricle)
			TOF
	745.2	Q21.3	Tetralogy of Fallot (TOF)
			dTGA
	745.1	Q20.3	Transposition of Great Arteries (TGA), Complete TGA (dextro-TGA), NOS or classical (dTGA, TGA)
	745.10		TGA
	745.19		TGA OS (dTGA, transposition of the great arteries)
			Interrupted arch
	747.11	Q25.21	Interrupted aortic arch