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ESTIMATE OF CARE NON-CONTINUITY AMONG MEDICAID BENEFICIARIES DIAGNOSED WITH CONGENITAL HEART DEFECTS IN FIVE METROPOLITAN GEORGIA COUNTIES: 1999-2010

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Abstract

ESTIMATE OF CARE NON-CONTINUITY AMONG MEDICAID BENEFICIARIES DIAGNOSED WITH CONGENITAL HEART DEFECTS IN FIVE METROPOLITAN GEORGIA COUNTIES: 1999-2010

By J'Neka Claxton

Purpose: Continuity in healthcare for individuals with a congenital heart defect (CHD) is an important public health issue. The aim of this study was to estimate the percentage of Georgia Medicaid beneficiaries diagnosed with a CHD sometime during 1999-2007 who also had a Medicaid-paid claim during 2008-2010. Medicaid claims paid during 2008-2010 were analyzed to determine the extent to which age, gender, and disease severity explain the likelihood of healthcare indicating their CHD.

Methods: Medicaid data were used to identify a CHD cohort, ages 9-62 years. Using multivariable logistic regression, odds ratios were calculated between age and having a Medicaid-paid claim during 2008-2010 and, among those with a claim, between age and having a CHD-related diagnosis on the claim.

Results: 5,944 patients had a CHD-related diagnosis on their Medicaid claim during 1999-2007; only 46% also had a Medicaid-paid claim during 2008-2010. After excluding those known to have left the catchment area, 52% had at least one Medicaid-paid claim; only 10% (522 of the 5,285) had a CHD-related diagnosis. Among 214 females less than 18 with a severe CHD classification, 115 (53%) had a Medicaid claim during 2008-2010, with 60% having a claim that included a CHD diagnosis. They were the most likely to have a Medicaid claim with a CHD diagnosis. With them as referent, males over 18 years regardless of CHD severity were less likely to have any Medicaid-paid claims during 2008-2010; further, among those with claims, almost every combination of age, sex, and CHD severity was less likely to have a Medicaid claim with a CHD diagnosis.

Conclusion: Among Medicaid patients in Georgia known to have CHD, during a three-year period surveillance of claims for CHD adolescents and adults, only 10% were identified by a Medicaid claim indicating CHD. As adolescents transition into adulthood, many no longer meet the requirements for Medicaid coverage in Georgia unless they are pregnant. Pregnant women with CHD need to be identified and referred for specialty care. Georgia needs to address implementing Medicaid expansion to cover individuals who otherwise may not be able to afford health coverage.

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TABLE OF CONTENTS

List of Abbreviations

ACHD	Adults with Congenital Heart Defects
AVCD	Atrioventricular Canal Defects
BWE	Backwards Elimination
CDC	Centers for Disease Control and Prevention
CHD	Congenital Heart Defects
CHIP	Children's Health Insurance Plan
CHOA	Children's Healthcare of Atlanta
CMS	Centers for Medicare and Medicaid Services
CNI	Conditional Index
DCH	Department of Community Health
DM	Diabetes Mellitus
FBR	Federal Benefit Rate
FISMA	Federal Information Security Management Act
FPL	Federal Poverty Level
GS	Gold Standard
GOF	Goodness of Fit
HL	Hosmer-Lemeshow
MACDP	Metropolitan Atlanta Congenital Defects Program
NHIS	National Health Interview Survey
PCS	Pediatric Cardiology Services
PPACA	Patient Protection and Affordable Care Act
ResDAC	Research Data Assistance Center

SCHIP	State Children's Health Insurance Plan
SSI	Supplemental Security Income Program
T1DM	Type I DM
T2DM	Type II DM
TOF	Tetralogy of Fallot
VDP	Variance decomposition proportions

CHAPTER I: BACKGROUND

Congenital Heart Defects (CHD)

Congenital heart defects (CHDs) are structural anomalies, present at birth, that affect the function of the heart (1,2). They comprise a wide spectrum of heart defects with varying levels of severity (3). Defects can involve the interior walls of the heart, the valves inside the heart, and the arteries and/or veins that carry blood to the heart or the body (1). CHDs result from a developmental failure early in pregnancy (4). The etiology of the disease is incompletely understood (5). Approximately 15-20% of CHDs have been linked to known genetic disorders, such as Down syndrome or Turner syndrome (2,5,6). However, the etiology of non-syndromal CHD is less clear. It has been proposed that genetic and environment exposures may be risk factors in the development of the disease (4,5).

Improved Longevity and Need for Population-based CHD Surveillance

CHDs are the most common type of birth defect, affecting about 1 in 110, or nearly 1% of births per year (6–9). Due to improved pediatric medical care, improved diagnosis, and the success of surgical repairs, it is estimated that 85-90% of infants diagnosed with CHD will survive to adulthood (4,9,10). That is, the population of adult survivors with CHD is rapidly growing, including those with severe lesions (11). The aging of the CHD population highlights the need for population-based surveillance data. In the United States, efforts to conduct a population-based surveillance of CHD have been limited to early childhood (6,12,13). Increased survivorship however, necessitates a comprehensive population-based surveillance of CHDs among individuals of all ages (i.e., newborn, children, adolescents, and adults) (6,12,13). Population-based surveillance data of CHDs

across the lifespan would allow for reliable estimates of disease prevalence, better characterization of the type and number of health services required and utilized, healthcare costs, information regarding late outcomes, including comorbidities, and mortality (6,13,14).

Quebec's CHD Population-based Prevalence Estimates

Due to the United States' current lack of data available to directly estimate the prevalence of CHD across the lifespan, estimates have been extrapolated from population-based data in Quebec. In 2000, a CHD prevalence study was conducted in Quebec, Canada by Marelli et al. to determine population estimates of CHD across the life-span (8). In Quebec, where healthcare access is universal, every individual is assigned a unique Medicare ID at birth that tracks all diagnoses and health services received until death (8). The Quebec Congenital Heart Disease Database was created by cleaning, de-duplicating and merging data from the following sources: (1) the physician services and drug claims database; (2) the hospital discharge summary database; and (3) the Quebec Health Insurance Board and Death Registry (8). In 2010, data updates were requested from the same administrative data sources used in their 1983-2000 study up through the year 2010. The final Quebec CHD database contains 28 years of data on 107,559 patients with a CHD diagnosis who were seen within the Canadian healthcare system from 1983-2010 (8). The goals of this study were to use this longitudinal database to estimate prevalence of CHD over the lifespan, and to compare the number of adults with a CHD to the number of children with CHD in the Quebec population from 2000-2010. From these data, the prevalence of CHD in adults in 2010 was 6.12 per 1,000, and 13.11 per 1,000 in children. From 2000 to 2010, CHD prevalence increased by 57% in adults and by 11% in children,

with adults now representing two-thirds of the CHD population (8). These prevalence estimates were then applied to the U.S. population in order to estimate the population of people possibly living with CHD in the U.S. in both 2000 and 2010. In 2000, it was estimated that 855,334 adults and 859,573 children were living with CHD. In 2010, an estimated 2 million people of all ages were possibly living with CHD, including ~959,000-1.5 million adults and ~975,000-1.4 million children. Marelli et al. suggests that improved care, decreased mortality, and improved diagnosis over the lifespan are likely contributors to the increasing prevalence of CHD among adults and children. Increased prevalence of an aging CHD population has been associated with lifelong comorbidities, which add to the disease burden of this population.

CDC's First U.S. Pilot Project: Surveillance of CHD among Adolescents and Adults

In an effort to fill the gap in understanding the true burden of disease in the U.S., the federal Patient Protection and Affordable Care Act (PPACA;PL 111-148, Section 10411) authorized the Centers for Disease Control and Prevention (CDC) to enhance and expand public health tracking of CHDs among adolescents and adults (13). In 2012, the CDC in collaboration with Emory University, the New York State Department of Health, and the Massachusetts Department of Public Health began work on a pilot project to develop a population-based tracking system of adolescents and adults with CHD (12). Methodologically, each site applied the same case definition to identify individuals with CHD (except for state-specific data providers) and the plans and progress of the project were guided by a 16-member External Guidance Committee consisting of medical and birth defect monitoring experts (15).

In Georgia, the surveillance database aimed to identify all adolescents and adults with a diagnosis of CHD residing within the state. The data surveillance system was constructed through the cross-linkage of multiple sources of pre-existing electronic administrative and clinical data, including Georgia vital records, Georgia Medicaid claim files, electronic medical records from seven hospitals, and data from the Metropolitan Atlanta Congenital Defects Program (MACDP) (14).This linked database was used to determine separate prevalence estimates for adolescents, aged 11-19, and adults, aged 20-64, who were diagnosed with at least one CHD related condition between 2008-2010 and were living in one of the five metropolitan Atlanta counties within the state of Georgia (see Table 1).

Prevalence Estimates from First Pilot Project

At the Emory site, CHD cases were identified from billing and medical/clinical records obtained from seven healthcare data sources: 1) Emory Healthcare; 2) St. Joseph's Hospital; 3) Grady Health; 4) Children's Health Care of Atlanta (CHOA); 5) Sibley Heart Center; 6) Pediatric Cardiology Services (PCS); and 7) Centers for Medicare and Medicaid Services (CMS). The data were evaluated using a two-source capture-recapture (CR) method for which separate age-based CR prevalence estimates, one for adolescents and another for adults, were calculated. CR methodology is a good method to apply to diseases like CHD, that have a complex etiology, are diagnostically complicated, and that require access to multiple data sources for complete case ascertainment (16). Over the pilot's three-year time frame, 1,858 adolescents cases were captured in at least one adolescent data source, and it was estimated that 3,718 (95% CI: 3,471-4,004) adolescents with CHD were living in a five county metro Atlanta area (Clayton, Cobb, DeKalb,

Fulton, and Gwinnett Counties) (16). For adults, during the same three-year prevalence period, 3,183 adult cases were captured in at least one adult data source, and it was estimated that 12,969 (95%CI: 12,873-18,915) adults with CHD were living in the five country metro Atlanta area (16). The separate CHD prevalence estimates were calculated by dividing age-specific populations, adolescent or adult, obtained from 2010 U.S. Census data by the respective estimated number of adolescent or adult CHD cases, and multiplying by 1,000. The prevalence among adolescents who were between 11-20 year olds was estimated to be 7.85 per 1,000 residents in 2010, and the prevalence among adults, aged 21-64 years, was estimated to be 6.08 per 1,000 residents (16). These estimates are similar to those found in Quebec, Canada by Marelli and colleagues (8).

Lifelong Care and Management of CHD

Complexity of CHD has been classified using severity levels developed by Marelli's hierarchy of CHD diagnostic codes (17). Severe CHDs are based on having the highest probability of cyanosis or early surgical intervention and include atrioventricular canal defects (AVCD), Tetralogy of Fallot (TOF), univentricular heart, transposition complex, truncus arteriosus, and hypoplastic heart syndrome (17). Patients with "severe" CHD classifications have more frequent and severe complications and require more specialized care compared to less severe patients (5). Less severe CHDs patients fall into one of four levels: Shunts, Valves, Shunts plus Valves, and Other (Appendix A) (17).

The substantial increase in life expectancy over the past decades for patients living with CHD has led to the finding that approximately 90% of children born with CHD survive into adulthood (18). However, even after successful primary treatment or surgery, many patients with CHD require lifelong cardiac surveillance. Care for adult congenital

heart disease (ACHD) can be categorized into 3 levels: 1) specialist care; 2) shared care; 3) non-specialist care (18). Specialist care is defined as healthcare follow-up given by a specialized ACHD cardiologist. Shared care is defined as healthcare follow-up given by a general adult cardiologist in collaboration with a CHD specialist. Lastly, non-specialized care is defined as healthcare follow-up provided by a general cardiologist or practitioner (18). Clinical guidelines and recommendations for care are given by what is deemed most appropriate for each type of heart defect. Patients with severe and complex CHD defects should receive checkups every 6 to 12 months by a specialist care ACHD cardiologist (18). Patients with moderate complexity defects should receive follow-up care every 1-2 years, preferably at a specialized center. However, if the CHD condition is uncomplicated or mild, then care can be undertaken at shared care facilities. Patients with simple heart defects need checkups every 3 to 5 years at either a non-specialized setting or at a shared care facility (18). Despite these guidelines, there is a false assumption that after initial treatment, defects are cured rather than repaired.

The Association of Diabetes and Congenital Heart Defects

As CHD patients live longer, there is a greater risk for them to acquire age-related co-morbidities. Thus, failure to adhere to the lifelong care guidelines has a clinical impact for adults with varying levels of CHD severity, especially those living with moderate or severe CHD defects. Hospitalization trends in the U.S. for ACHD patients show an increase in comorbidities over time (19). One of these co-morbidities is Diabetes Mellitus (DM) which is a condition that occurs when a person's glucose level is above normal due to a failure of the pancreas to produce enough insulin or a situation in which insulin cannot be used normally. There are two types of DM, Type I and Type II. Type I DM

(T1DM) is typically diagnosed at a young age, and only about 5% of those with DM have this type (20). Type II DM (T2DM) refers to adult onset DM and about 95% of all DM patients have this type (20).

Adults with DM are high healthcare utilizers and are at higher risk for hospitalization compared to the general population. Adults with CHD are also considered a high healthcare utilizer group since ACHD patients are known to have numerous hospitalizations, high usage of medical technology, and increased healthcare use from a multidisciplinary team of providers (21). However, little is understood regarding the effects of DM in the ACHD population on healthcare utilization and hospitalization. Oandasan conducted a cross-sectional study of ACHD patients to examine the relationship between hospitalization and DM among the ACHD population (21). Individuals included in the study were seen at one of three Emory University hospital facilities and between the ages of 21-64 years. Results revealed that among CHD patients, the odds of being hospitalized for a patient diagnosed with DM is 7.8 times (95% CI: 5.4, 11.3) that of a patient without a DM diagnosis (21). After controlling for CHD severity, hypertension, and hyperlipidemia, it was found that the odds of being hospitalized for diabetic ACHD patients were 4.2 times (95% CI: 2.9, 6.2) those of non-diabetic ACHD patients (21). This study highlights the healthcare burden of comorbidities, such as DM, among the ACHD population and emphasizes that healthcare and treatment of CHD patients should encompass both short- and long-term goals.

Access to Care

Access to affordable and quality healthcare services is essential to increasing the quality of healthy living for the entire population. However, there are key barriers that limit healthcare access for many including lack of health insurance, family income, race

and/or ethnicity, place of residence, and family structure (single parent vs. two parent homes) (22). For individuals and families with low incomes, barriers to care are slightly different than the general barriers deterring access to care for the general population. For this population, barriers to care include lack of stability in insurance coverage for those who are publicly insured, poor access to healthcare services when insured, and unaffordable costs related to medications and copays (23). When considering individuals with special health care needs, like CHD, barriers to care prior to the PPACA include limited insurability due to pre-existing conditions. Implementation of the PPACA did not eliminate other barriers such as lack of education regarding their own health care needs, unemployment, lack of proximity to a specialized care center, and lack of qualified adult-level caregiving personnel (6,24). Access to care creates a significant barrier to estimating the true number of CHD patients.

Medicaid

Public health insurance programs, such as Medicaid, have improved access to care for many families with low incomes. The Medicaid Program, enacted in 1965 under Title XIX of the Social Security Act, was created to provide health care coverage to groups of low-income people, who otherwise may have no or inadequate medical insurance. In all states, covered groups now include children, pregnant women, families with dependent children, people aged 65 or older, and blind and/or disabled individuals whose income is insufficient to meet the cost of necessary medical services (25–27). The U.S. federal government establishes general guidelines for the program; however, the Medicaid program requirements and eligibility criteria are established by each state (26).

A main goal of the PPACA is to extend health coverage to many of the non-elderly uninsured individuals nationwide, including many of the 1.8 million uninsured Georgians. The PPACA accomplishes this by establishing new coverage pathways, including expansion of Medicaid to cover nearly all non-elderly adults up to 138% FPL, and by providing premium subsidies to most individuals up to 400% FPL to purchase coverage on the Health Insurance Marketplace (28). However, based on a decision when PPACA took full effect, Georgia was one of 23 states which did not opt to implement the PPACA Medicaid expansion (28). As of January 2016, it is one of 19 states which have not expanded Medicaid (29).

Georgia Medicaid Eligibility

Georgia has not yet accepted expanded Medicaid. Rather, in Georgia, income eligibility levels for Medicaid enrollment that are determined by age and group apply only to the low-income groups mentioned above. Each year by the Federal government defines the federal poverty level (FPL), for different family sizes (30). Eligibility is based on a percentage of the FPL, typically up to 200 percent of the FPL (25). Children from ages 0-1 can qualify for Medicaid benefits when household income is at or below 210 percent of the FPL in 2016. Income limits ranged from a low of 185 percent of the FPL in 2000, to high of 235 percent of the FPL in 2003-2004 (31). Children from ages 1-5 qualified for Medicaid benefits when their household income was at or below 133 percent of the FPL from 2000-2012, however, the limit increased to 154 percent in 2014 (32). Children from ages 6-18 qualified for Medicaid benefits when their household income was at or below 100 percent of the FPL from 2000-2012, however the limit increased to 138 percent in 2014 (33). From 2004-2013, pregnant women with an income at or below 200 percent of

the FPL were eligible for Medicaid. This eligibility increased to 225 percent of the FPL in 2014 (34).

A Snapshot of Georgia Medicaid Beneficiaries

The Georgia Department of Community Health (DCH) Medicaid Division oversees the Georgia Medicaid program which administers health care for approximately 1.6 million low-income children, pregnant women, people who are aging, blind and disabled, representing approximately 18.8% of the total Georgia population (35). In 2011, Georgia Medicaid enrollees had the following social and demographic characteristics: 58% female, 42% male (36); 44% white, 47% black, 1% Hispanic, and 8% other (37); 60% 0-18 year olds, 9% 19-26 year olds, 12% 27-44% year olds, 10% 45-64 year olds, and 9% 65 year olds and older (38). In 2011, the distribution of Medicaid enrollees by enrollment group were 59% children (<=18 years of age), 16% adult (19-64 years of age), 16% disabled adults, and 9% aged (>=65 years of age) (39). Disabled included people under age 65 years old who were eligible due to a disability.

State Children's Health Insurance Program (SCHIP)

The State Children's Health Insurance Plan (SCHIP) was created in 1997 (9,25,26,40) as part of the Balanced Budget Act (BBA) to provide insurance coverage to uninsured, low-income children above Medicaid income eligibility thresholds, typically up to 200 percent of the FPL (25). This legislation enabled states to design their Children's Health Insurance Plan (CHIP) programs in one of three ways: (1) *Separate CHIP* - a program separate from Medicaid for uninsured, low-income children who meet the requirements of section 2103 of the Social Security Act; (2) *Medicaid expansion CHIP* - a program that expands Medicaid eligibility to optional targeted low-income children who

meet the requirements of section 2103 of the Social Security Act; and (3) *Combination CHIP* - a program that implements both a Medicaid expansion and a separate CHIP (25,41). In 2006, 18 states operated separate CHIPs only, 11 states and the District of Columbia expanded Medicaid only, and 20 states applied the combination approach (25).

Georgia's PeachCare for Kids®

The Georgia DCH Medicaid Division also oversees the Georgia's s*eparate CHIP*, PeachCare for Kids®. PeachCare for Kids® is a comprehensive plan which began in Georgia in 1998. From 2000-2013, PeachCare for Kids® served children through the age of 18 ((31),(38) who lived in households with incomes at or below 235 of the FPL (34). In January 2014, the family's income limit increased to 252 percent of the FPL (43). PeachCare for Kids® charges families premiums and requires a co-payment for children ages 6 or older (42). This program's health benefits include primary, preventative, specialist, dental, and vision care (27,35,42) as well as hospitalization coverage, emergency room services, prescription medication and mental health services (35). Over the last decade, PeachCare for Kids® ' average annual enrollment has ranged from 230,000 to over 350,000 children (44).

Medicaid and CHIP Coverage Gaps

As of 2012, Georgia had among the highest uninsured rates in the country, with more than one in five Georgians (22%; 1.8 million people) lacking insurance (28). Approximately 90% of these uninsured Georgians are low-income individuals who have an income below 400% FPL. Six in ten uninsured people in Georgia are of color (28). Georgia's failure to expand Medicaid leaves nearly 600,000 low-income adults uninsured - adults who otherwise would be eligible for Medicaid if the state of Georgia expanded

their Medicaid program (28). As a result, these individuals fall into a "coverage gap" of having incomes above Medicaid eligibility, but below the lower limit for Marketplace premium tax credits (45). The age distribution of those low-income adults who fall into this coverage gap is: 18-39 (60%), 40-49 (20%), and 50-64 (20%) (46).

Insurance Transition and Disparities

Lack of health insurance is a critical issue during young adulthood. For many young adults, insurance coverage is often dynamic during this period. Often in transition to young adulthood, many lose eligibility if covered under their parents' private insurance (the PPACA permits children to be covered by parents' insurance until they reach their 26th birthday) or if their coverage ends at age 19 for public programs (47). Adams et al. conducted a study to understand the patterns and disparities in health insurance from adolescence through the early 30's. Data from approximately 50,000 respondents aged 13 to 32 years from the 2002 and 2003 National Health Interview Survey (NHIS) was used.(47). Results revealed that insurance coverage follows a U-shaped curve across the age categories. Rates were highest among young adolescents (aged 13-14 years) and 31-32 year olds. The lowest insurance coverage rates were among 23-24 year olds. A steep decline in insurance rates was observed after 18 years and continued through the mid-20s (47), and this drop in coverage predominantly affected disadvantaged groups, including those with low incomes and those with special health care needs (47). Gaps in insurance coverage substantially reduced access to care and utilization of necessary care (47,48).

Medicaid and CHD

Medicaid, in many ways, acts to bolster our nation's health care system by providing a safety net for many of the poorest, sickest, and most disabled individuals. In

2009, national health insurance covered was almost 60 million Americans, including 8.5 million non-elderly persons with disabilities (49). Individuals qualify for Medicaid solely on their low income status if they fit into a coverage group, such as pregnant women or children, and meet their state's income limit for that particular group (50). Individuals also qualify for Medicaid based on their disability status, and must meet the financial qualifications for Medicaid coverage in addition to meeting categorical criteria that are often tied to the Supplemental Security Income Program (SSI) (49). SSI is a strictly need-based program, for which individuals qualify based on income and assets (51). It is available for low-income, disabled individuals who have never worked (52).

Persons with CHD may qualify for Medicaid through SSI, if the defect is so severe that the individual is unable to work or has functional limitations (53,54). SSI eligibility is determined through two steps: 1) individuals must meet the income and assets limits; and 2) individuals must prove that they are medically disabled. The income limit for the program is based on the federal benefit rate (FBR) (55). Currently, in 2016, the FBR is $733 per month for individuals, and $1,100 per month for couples (55). To qualify, one's monthly income must not exceed the FBR. Unlike the income limits, the SSI eligibility criteria to be considered medically disabled differs among children (under 18) and adults. For children, once the income and assets qualifications are met, the child must meet three additional requirements. First, the child is not working or earning over $1040 per month (56). Second, the child has "marked and severe" functional limitations that interfere with his/her ability to function at an age appropriate level. Finally, the child has been disabled for the past 12 months, or is expected to be disabled for 12 or more months (56). Taking into consideration that these requirements are met, a child with CHD may be

approved automatically if his or her condition is classified in the "impairment listings." There are three main listings, 1) 104.06 congenital heart disease, 2) 104.02 chronic heart failure, or 3) 104.05 recurrent arrhythmias, for which a child can be approved for benefits given that he or she meets all the criteria within that listing (53). If a child doesn't meet the requirements of any of the above listings, he/she may still qualify if their symptoms are so severe that they are "functionally equal" to the listings. That is, a child's symptoms must result in a "marked" limitation in two areas of functioning or an "extreme" limitation in one area. These areas of functioning include: 1) acquiring and using information; 2) attending and completing task; 3) interacting and relating to others; 4) moving about and manipulating objects; 5) caring for self; and 6) health and physical well-being (53). The medically disabled requirements for an adult with CHD include meeting one of the requirements under the 4.06 symptomatic congenital heart disease listing (54). If an adult doesn't meet the requirements of the above listing, he/she may still qualify for disability benefits, however, approval is more difficult. At this stage, the individual must prove that the congenital heart defect limits his/her ability to work full-time and reduces productivity by 20% (54).

At the age of 18, children who receive SSI will be reevaluated as adults through an "age 18 redetermination" process. Due to the different expectations placed on children and adults, the qualification process of an adult focuses on the individual's ability to work versus his/her functioning abilities (57). However, children who qualified for SSI because they met or equaled the requirements of a listing are more likely to meet the requirements of the adult listings. That is, childhood impairments that are known to continue after age 18 generally transfer to adult impairments that meet the disability listings (57). For

example, a child with CHD who qualified under the 104.06 listing will likely qualify under the 4.06 listing as an adult. In contrast, children who qualified for SSI due to their poor functioning in one or more of the functional domains will have to provide additional evidence to meet the adult requirements (57). Social Security acknowledges the difference between children turning 18 and those who are already adults. In an attempt to get a clearer picture of the older adolescent and his/her impairments, Social Security reviews many more sources of evidence, such as statements from school programs, therapists or social workers, before deciding whether or not benefits will be continued (57). However, many transitioning adolescents and young adults do not meet the adult defined requirements and thus, lose their benefits. An estimated 57% of individuals have their benefits continued, while 43% are determined not disabled, having their benefits terminated after this redetermination process (58).

Transitioning Care from Adolescence to Adulthood

Older adolescents experience a window of vulnerability as they transition from pediatric healthcare to adult healthcare services. Successful transition is especially important for individuals with special health care needs such as CHD. Gurvitz et al. conducted a multicenter, prospective, cross-sectional study to quantify the prevalence of gaps in cardiology care and identify predictors of gaps (59). They defined an overage gap as a > 3-year interval between any cardiology appointments (i.e., internal medicine, pediatric or adult congenital cardiology) and reported that 42% of patients with CHD reported a gap in cardiology care. Complexity of CHD was associated with gaps in care. An estimated 59% of mild CHD patients, 42% of moderate CHD patients, and 26% of severe CHD patients reported care gaps (59). The mean age at the first gap in healthcare

was 19.9 years, with the top 5 reasons for leaving cardiology care being: 1) ’changing or losing insurance‘; 2) ’financial problems‘; 3) ’lost track in time‘; 4)’decreased parental involvement‘; and 5) ’moved‘ (59). However, the underlying reasons for these gaps remains unclear. Additionally, there is limited information regarding individuals with CHD who are being missed in the healthcare system.

Continuity in healthcare for individuals with CHD is an important public health issue. It is especially important for low income individuals who have additional barriers to accessing care. The aim of the proposed study is to examine a population of adolescents and adults with CHD, who are Medicaid beneficiaries, to estimate what percentage of CHD-diagnosed individuals covered by Medicaid from 1999-2007 were seen during the surveillance period of 2008-2010. Multiple factors play a role in whether individuals with CHD continue care, such as sex, CHD severity, age, and race. A goal of this study is to understand how these risk factors differ among CHD patients who continue specialized care and those who do not continue specialized care.

CHAPTER II: METHODS

Hypotheses

For Medicaid beneficiaries who reside within the five metro-Atlanta county catchment area (Clayton, Cobb, DeKalb, Fulton, and Gwinnett Counties) and who had a CHD-related ICD-9-CM diagnosis on a Medicaid claim during 1999-2007, it is hypothesized that:

a. age as of 1/1/2008 is associated with whether or not they had a Medicaid-paid claim during the 2008-2010 surveillance period.
b. being older (age) (>17 years as of 1/1/2008), male (sex), and having a less "severe" CHD classification (severity) are associated with not having a Medicaid-paid claim during the 2008-2010 surveillance period.
c. among those with a Medicaid claim during the 2008-2010 surveillance period, age as of 1/1/2008 is associated with whether or not at least one claim included a CHD diagnosis.
d. Among those with a Medicaid claim during the 2008-2010 surveillance period, being older (age) (>17 years as of 1/1/2008, male (sex), and having a less "severe" CHD classification are associated with not having a CHD diagnosis.

Study Design and Population

This study is part of a pilot project conducted by Emory University in collaboration with the CDC to develop a population-based surveillance system of adolescents and adults with CHD in the state of Georgia with primary focus on the five metropolitan Atlanta counties (Clayton, Cobb, DeKalb, Fulton, and Gwinnett). The objectives of this surveillance project included estimating the prevalence of CHD within

the five metro-Atlanta counties during 2008-2010 and acquiring a better understanding of survival rates and healthcare utilization among adolescents and adult CHD survivors. This thesis contributes to the larger project by examining Georgia Medicaid records from 1999-2007 and comparing these to Georgia Medicaid records from the 2008-2010 to assess care continuity. All individuals in the sample were covered by Medicaid at some time during this 12-year period (1999-2010), but only those with a CHD diagnosis code on a Medicaid claim during the 2008-2010 surveillance period were included in the pilot study. Those with a CHD diagnosis coded on a Medicaid claim between 1999 and 2007 would have been in the pilot study only if they also had a CHD diagnosis on a Medicaid claim during 2008-2010.

Secondary data were obtained from Emory's population-based surveillance data repository which included Georgia Medicaid administrative claims data from January 1, 1999 through December 31, 2010 for individuals with a CHD diagnosis. These data were obtained from the Centers for Medicare and Medicaid Services (CMS) via Research Data Assistance Center (ResDAC), a CMS contractor which assists academic, government, non-profits and for-profits organizations acquire Medicaid and/or Medicare datasets. The sample of Georgia Medicaid beneficiaries residing in the five metro-Atlanta counties included 5,944 CHD patients age 9-62 as of 1/1/2008. The outcome variables were: 1) having a Medicaid claim from 2008-2010; and 2) having a CHD ICD-9-CM diagnostic code on a Medicaid claim from 2008-2010. Predictor variables considered in statistical models were age, sex, and CHD severity; race was omitted from the analytic dataset due to scarcity once initial demographics were conducted.

Data Management and IRB

The parent pilot study received approval from Emory University's Institutional Review Board (IRB) (#IRB0000064051). All data were stored on a secure FISMA-compliant (Federal Information Security Management Act) network storage device drive at Emory University, Rollins School of Public Health Information Technology Department server system and maintained by authorized IT personnel and study researchers. All data for this secondary analysis were cleaned, de-duplicated, and linked prior to analysis. Protected Health Information (PHI) were removed and replaced with non-identifiable-IDs to maintain confidentiality.

Inclusion and Exclusion Criteria

Individuals included in the study were adolescent and adult patients with a CHD diagnosis, who were at least 9 years of age and not older than 62 years of age by January 1, 2008, who resided in one of the five metro-Atlanta area counties (Clayton, Cobb, DeKalb, Fulton, and Gwinnett), and who were identified as having a CHD by having at least one GA Medicaid claim with for their CHD condition anytime between January 1, 1999 to December 31, 2007. All patients had at least one of the 55 ICD-9-CM CHD-related diagnostic codes (Appendix A) and were classified into one of five severity levels using Marelli's hierarchy of CHD diagnostic codes (17) (Appendix A). Patients who were not alive, younger than 9 years of age, or older than 62 years of age as of 01/01/2008, and resided outside the metro-Atlanta catchment area during 2008-2010 were excluded.

Outcome Variables

The outcomes or dependent variables were: 1) having a Medicaid claim during 2008-2010; and 2) having a CHD-related Medicaid claim during 2008-2010. Having a Medicaid claim from 2008-2010 was defined as having at least one Medicaid claim any

time during the 2008-2010 surveillance period. This outcome variable was binary and coded ‘0’ for those who did not have a Medicaid claim and ‘1’ for those who had at least one Medicaid claim any time during this three-year period. A CHD-related Medicaid claim during the 2008-2010 surveillance period was defined as having at least one Medicaid claim with a CHD-diagnosis any time during this three-year period. This outcome variable was binary and coded ‘0’ for those who did not have a Medicaid claim with a CHD-diagnosis and ‘1’ for those who had at least one Medicaid claim with a CHD-diagnosis any time during this three-year period.

Predictor Variables

The predictor variables included in this study were age, race, sex, and CHD severity. These variables were considered because they are well established risk factors for transition into adult care or care maintenance for individuals with CHD.

Age

Patients in this study were between the age of 9 and 62 as of January 1, 2008. Age was classified into five age groups: 9-11, 12-13, 14-17, 18-24, and 25-62 for descriptive statistics. For statistical modeling, age was categorized into 3 categories: ‘1’ for those < 18 years, ‘2’ for those 18-24 years, and ‘3’ for those 25-62 years. This variable was determined by subtracting the patient’s date of birth from 01/01/2008. The youngest age grouping, <18, served as the reference group.

Race

Race was classified into the following 4 categories: ‘1’ for whites, ‘2’ for blacks, ‘3’ for other (i.e., American Indian/Alaskan Native, Asian, or Native

Hawaiian/other Pacific Islander), and ’4’ for unknown. Whites served as the reference group. While race was included in the descriptive table, it was omitted from the modeling and not included in any further analyses due to the amount of missing data.

Sex

Sex was coded ‘0’ for females and ‘1’ for males. Females served as the referent group for modeling.

CHD Severity

This variable was classified into five groupings based on Marelli et al.’s hierarchical classification of CHD (Appendix A): 1) Severe; 2) Shunts; 3) Shunt plus Valves; 4) Valves; 5) Other unspecified CHD anomalies. Other unspecified CHD anomalies served as the reference group in modeling.

Statistical Analysis

Simple descriptive statistics were performed for each predictor variable. Frequencies for race, sex, and CHD severity were computed within each age category. For bivariate analyses, chi-square was used to test the differences in characteristics (i.e., age, sex, CHD severity) of those who had a Medicaid claim during the 2008-2010 surveillance period and those who did not, and those whose Medicaid claims included a CHD diagnosis during the 2008-2010 surveillance period and those whose claims did not have a CHD diagnosis during the 2008-2010 surveillance period. Chi-square was applied to test the differences in characteristics of: 1) those residing within the five metro-Atlanta counties from 1999-2010 and who had a Medicaid claim during the 2008-2010 surveillance period, and those residing outside the five metro-Atlanta counties between 1999- 2007 but moved into the five metro-Atlanta counties during the 2008-2010

surveillance period and had a Medicaid claim during that three-year surveillance period; and 2) those residing within the five metro-Atlanta counties from 1999-2007, but who moved in Georgia but outside the catchment area during the 2008-2010 surveillance period and had a Medicaid claim during the three-year surveillance period, and those residing outside the five metro-Atlanta counties between 1999-2007 and moved into the five metro-Atlanta area during the 2008- 2010 surveillance period and had a Medicaid claim during that three-year surveillance period.

Among Medicaid beneficiaries residing within the five metro-Atlanta counties who had a CHD-diagnosis during 1999-2007, two sample datasets were constructed to assess the relationship between the predictor variables and each outcome variable. The first sample included 5,285 CHD patients who had either a Medicaid claim and resided within the five metro-Atlanta counties during 2008-2010 or who did not have a Medicaid claim and assumed to not have moved out of the catchment area during 2008-2010. The second sample included 2,735 patients who had a Medicaid claim, either with or without a CHD–related ICD-9-CM diagnosis during 2008-2010.

To develop the most parsimonious model to test the association between the predictors and each outcome, the following strategy was utilized. For both samples, a collinearity assessment was conducted to address any potential relationships of the predictors to one another. It was assessed by determining if any conditional indexes (CNIs) were >30. For CNIs > 30, the variance decomposition proportions (VDPs) were reviewed to determine which variables had VDPs > 0.5. More than one variable with a VDP > 0.5 suggested collinearity and thus the variable with the highest VDP value was removed and the process repeated with the reduced model. Interaction was assessed by

carrying out a chunk test followed by conducting a backwards elimination (BWE) logistic regression analysis. The BWE method eliminates non-significant interaction terms one at a time. Interaction assessment was followed by assessing confounding using the all possible subsets of the Gold Standard (GS) model approach. Confounding was considered present if the OR of a given model in the all possible subsets was greater ± 10% of the GS OR. Subset models that were within 10% of the GS were compared to the GS to determine if there were any gains in precision. Finally, Goodness of Fit (GOF) was assessed using the Hosmer-Lemeshow (HL) test for logistic regression. This test was used to determine how well the model fits the data or in other words, if the model was correctly specified. It the *p*-value produced is high, then the model is said to pass the test, but if the p-value produced is low, below .05, then the model is not well specified and the model is rejected. So, models with a p-value < 0.05 are considered to lack fit. Logistic regression was employed to determine: 1) the odds of not having a Medicaid claim during the three-year surveillance period compared to the odds of having one during the same time frame; 2) among those with a claim, the odds of no CHD diagnosis on any claim during the three-year surveillance period compared to the odds of having at least one CHD diagnosis on a Medicaid claim during this same 2008-2010 surveillance period. All analyses were conducted using SAS 9.4 (Cary, NC).

CHAPTER III: MANUSCRIPT

ESTIMATE OF CARE NON-CONTINUITY AMONG MEDICAID BENEFICIARIES DIAGNOSED WITH CONGENITAL HEART DEFECTS IN FIVE METROPOLITAN GEORGIA COUNTIES: 1999-2010

J'Neka Claxton

Introduction

Congenital heart defects (CHDs) are the most common type of birth defect, affecting about 1 in 110, or nearly 1% of births per year (6–9). CHDs are structural anomalies, present at birth, that affect the function of the heart (1,2). They comprise a wide spectrum of heart defects with varying levels of severity (3). Advances in pediatric medical care, improved diagnosis, and the success of surgical repairs in infants with CHD has resulted in an estimated 85-90% survival into adulthood (4,9,10). However, even after successful primary treatment or surgery, many patients with CHD require lifelong cardiac surveillance. Adult congenital heart disease (ACHD) health care can be categorized into 3 levels: 1) specialist care; 2) shared care; 3) non-specialist care (18). Specialist care is defined as healthcare follow-up given by a specialized ACHD cardiologist. Shared care is defined as healthcare follow-up given by a general adult cardiologist in collaboration with a CHD specialist. Lastly, non-specialized care is defined as healthcare follow-up provided by a general cardiologist or practitioner (18). Clinical guidelines and recommendations for care are given by what is deemed most appropriate for each type of heart defect. Despite these guidelines, there are gaps in care which in part can be attributed to a false assumption that after initial treatment, defects are cured rather than repaired.

In addition, as CHD patients live longer, the risk of acquiring age-related co-morbidities increases. Access to affordable and quality healthcare services is essential to

increasing the quality of healthy living and management of comorbidities, especially for this population. However, there are key barriers that limit healthcare access for many including lack of health insurance, family income, race and/or ethnicity, place of residence, and family structure (single parent vs. two parent homes) (22). Lack of health insurance is a critical issue during young adulthood. The length of time a person goes without health coverage has serious implications on access and utilization of care. That is, as the interval of time without insurance increases, the likelihood of experiencing problems accessing and utilizing necessary care increases (47,48). For many young adults, insurance coverage is often dynamic and variant and can serve as a barrier to successful transitioning from pediatric into ACHD care.

Continuity in healthcare for individuals with CHD is an important public health issue. It is especially important for low income individuals who have additional barriers to accessing care. The aim of the proposed study is to estimate what percentage of Medicaid covered CHD-diagnosed individuals from 1999-2007 received care as a Medicaid beneficiary during the surveillance period of 2008-2010 and to explore how age, gender, and disease severity may be associated with the likelihood of Medicaid-paid care for individuals aged 9-62 on January 1, 2008. It is hypothesized that for Medicaid beneficiaries residing within the five metro-Atlanta counties (Clayton, Cobb, DeKalb, Fulton, and Gwinnett Counties) who had a CHD-diagnosis code on at least one of their Medicaid claims during 1999-2007, being older (age) (>17 years as of 1/1/2008), male (sex), and having a less “severe” CHD classification (severity) are associated with less likelihood of receiving Medicaid-paid care and less likelihood of a CHD diagnosis among those who did receive Medicaid-paid care.

Methods

Study Design and Population

The current study focuses on the continuity of care among adolescent and adult CHD patients insured by Medicaid over a twelve-year period. It was part of a larger Centers for Disease Control and Prevention pilot CHD surveillance project with Emory University aimed at acquiring a better understanding of survival rates and healthcare usage among adolescents and adults living with CHD.

Secondary data were obtained from Emory's population-based surveillance data repository which included Georgia Medicaid administrative claims data from January 1, 1999 through December 31, 2010 for individuals who had a CHD diagnosis sometime over that 12-year time frame. These data were obtained from the Centers for Medicare and Medicaid Services (CMS) via Research Data Assistance Center (ResDAC), a CMS contractor. The total sample consisted of 5,944 CHD patients, age 9-62 years. The outcomes of interest were: 1) having a Medicaid claim during the 2008-2010 surveillance period; and 2) having a CHD-related Medicaid claim during the 2008-2010 surveillance period. Predictor variables considered in statistical models were age, sex and CHD severity; although race was captured in the demographics, it was omitted from modeling due to scarcity.

Case Definition and Exclusion Criteria

All CHD patients had at least one of the 55 ICD-9-CM CHD-related diagnostic codes (Appendix A) on at least one Georgia Medicaid claim anytime between January 1, 1999 to December 31, 2007, resided within one of the five metro-Atlanta counties (Clayton, Cobb, DeKalb, Fulton, and Gwinnett), and were at least 9 years of age and not older than 62 years of age as of January 1, 2008. CHD patients were classified into one of

five severity levels using Marelli's hierarchy of CHD diagnostic codes (17): (1) Severe; (2) Shunts; (3) Valves; (4) Shunts plus Valves; and (5) Other CHD Anomalies (Appendix A). Patients who were not alive, younger than 9 years of age or older than 62 years of age as of 01/01/2008, and resided outside the metro-Atlanta catchment area during 2008-2010 were excluded.

Predictor Variables

The predictor variables included in this study were age, race, sex, and CHD severity. These variables were considered because they are well established risk factors for transition into adult care, or care maintenance for individuals with CHD in the literature.

Directed Acyclic Graph (DAG)

A Directed Acyclic Graph (DAG) was constructed to evaluate the association between the predictor variables (age, sex and CHD severity), and the two dichotomous outcome variables (having a Medicaid claim during the 2008-2010 surveillance period and having a CHD-related diagnosis on a Medicaid claim during the 2008- 2010 surveillance period), accounting for the influence of confounding and interacting variables. Although race was not addressed analytically due to its scarcity in the dataset, it was included in the DAG as it has been noted within the literature as a key barrier limiting healthcare access (Figure 1).

Statistical Analysis

SAS version 9.4 (SAS Institute, Inc. Cary, North Carolina) was used for all analyses, and the alpha level of 0.05 was used to determine statistical significance. Simple descriptive analyses were performed for each predictor variable. Frequencies for race, sex, and CHD severity were computed within each age category. Among individuals residing within the five metro-Atlanta counties who were covered by Medicaid and had a CHD-

diagnosis on a claim during 1999-2007, two sample datasets were constructed to assess the relationship between the predictors and each outcome variable. The first sample included 5,285 patients who resided within the five county area and who either did or did not receive Medicaid-paid care during the 2008-2010 surveillance period. The second sample included a subset of 2,735 who did receive care, with attention to whether that care included a CHD diagnosis on at least one Medicaid claim during the same three-year period.

To develop the most parsimonious model testing the association between the predictors and each outcome, the following strategy was utilized. Bivariate analysis was used to test the differences in characteristics (i.e., age, sex, CHD severity) of those who had a Medicaid claim during 2008-2010 and those who did not and, among those with a claim, those with or without a CHD diagnosis during 2008-2010. For both analyses, a collinearity assessment was conducted to address any potential relationships of the predictors to one another. Interaction was assessed by carrying out a chunk test followed by the Backwards Elimination (BWE) method which eliminates non-significant terms including interaction terms, one at a time. Interaction assessment was followed by assessing confounding using the all possible subsets (the Gold Standard (GS) model approach). Confounding was considered present if the OR of a given model in all possible subsets was greater ± 10% of the GS OR. Subset models that were within 10% of the GS were compared to the GS to determine if there were any gains in precision. Finally, Goodness of Fit (GOF) using the Hosmer-Lemeshow (HL) test was applied to determine how well the models fit the data, or in other words, to determine if the models were well specified. Logistic regression was used to determine: 1) the odds of not having a claim

during the three-year surveillance period compared to the odds of having a claim during this same period; and 2) among those with at least one claim, the odds of not having a CHD diagnosis during the three-year surveillance period compared to the odds of having a CHD diagnosis on at least one Medicaid claim during this same period.

Results

Descriptive Statistics

Overall, a total 5,944 individuals were included in this study. Of those, 2,735 (46%) resided within the five metro-Atlanta county catchment area and had a Medicaid claim during the 2008-2010 surveillance period, while 659 (11%) resided in Georgia but outside the five counties and had a Medicaid claim in 2008-2010. There were 2,550 (43%) CHD Medicaid beneficiaries who had at least one Medicaid claim with a CHD diagnosis during 1999-2007, but who had no Medicaid claim in 2008-2010 (Table 2a & b). Age was distributed in the following way: 9-11 years: 1,831 (31%); 12-13 years: 465 (8%); 14-17 years: 620 (10%); 18-24 years: 833 (14%); and 25-62 years: 2,195 (37%) (Table 2a). While for teens and young adults, gender was equally distributed ranging from 53% males to 47% females for the youngest age group, 50% females to 50% males for 12-13 year olds, and 51% males to 49% females among 14-17 year olds, there was a slight shift in the gender distribution for the 18-24 year olds with females slightly outnumbering males, 54% vs. 46%, respectively, and among the oldest aged cohort, females significantly outnumbered males 3 to 1 (73% females to 27% males). A similar pattern for gender holds true for the data in Table 3a.

Of the 2,735 patients who resided within the five county catchment area who had a Medicaid claim in 2008-2010, 522 (19%) of them had a CHD diagnosis on a Medicaid claim, while 2,213 (81%) did not have a CHD diagnosis on a Medicaid claim (Table 3a &

b). For this group, age was distributed in the following way: 9-11 years: 752 (28%); 12-13 years: 252 (9%); 14-17 years: 369 (13%); 18-24 years: 350 (13%); and 25-62 years: 1,012 (37%) (Table 3a). With respect to gender, a similar pattern for the data in Table 2a holds true for the data in Table 3a with a significant shift favoring more females (71%) to males (29%) among the oldest age group, 25-62 year olds.

In both samples, severity groupings were distributed similarly across all age groups (Table 2b & 3b). Patients with CHDs classified as *Shunts* or *Shunts + Valves* made up the largest proportions, while those with a CHD classified as *Valves* represented the smallest proportion in each age group. For those less than 18 years, a greater proportion of CHDs were classified as *Shunts*. For example, for those age 9-11, severity was distributed as: *Severe: 11%; Shunts: 55%; Shunts +Valves: 18%; Valves: 2%; and Other: 14%* (Table 2b). For those 18 and older, a higher percentage of CHDs were classified as *Shunts+ Valves.* For instance, for those 25-62 years, severity was distributed as: *Severe: 9%; Shunts: 17%; Shunts +Valves: 38%; Valves: < 1%; and Other: 36%* (Table 2b). A similar pattern for CHD severity holds true for the data in Table 3b.

Initial chi-square tests were conducted to assess the associations between covariates and the outcomes (i.e., having a Medicaid claim during 2008-2010 and a having a CHD-related Medicaid claim during 2008-2010). Sex (from Table 2a) and CHD severity (from Table 2b) were each found to be independently and significantly associated with having a Medicaid claim during the three-year surveillance period for 18-24 year olds. For CHD Medicaid beneficiaries who were 25-62 years old, sex was significantly associated with having a CHD-related Medicaid claim during 2008-2010 with females outnumbering males 3 to 1 (Table 3a). CHD severity was found to be significantly associated to this

outcome for all age categories, in that those who did not have at least one CHD-related Medicaid claim during the three-year period had a different distribution in regards to CHD severity than those who had a CHD-related Medicaid claim during the same time (Table 3b). There were no differences in the characteristics of those that moved into the five metro-Atlanta catchment area during 2008-2010 compared to those that lived in the five metro-Atlanta catchment area during 1999-2010 and those who moved out of the catchment area during 2008-2010 (data not shown).

The distribution of CHD severity by age and sex for the total study population of Medicaid patients as well as by having a Medicaid-paid claim or not during 2008-2010 is seen in Table 2c. Those < 18 years make up ~50% of the total population, for which 50% did or did not have a Medicaid-paid claim during 2008-2010. Among 214 females less than 18 with a severe CHD classification, 115 (53%) had a Medicaid claim from 2008-2010 (Table 2c). These adolescents were the most likely to have a Medicaid claim with a CHD diagnosis from 2008-2010. In contrast, males over 18 years regardless of CHD severity were less likely to have any Medicaid-paid claim during 2008-2010. For example, among males 25-62 with an *Other* CHD classification, 42% (101 of 240) had a Medicaid claim from 2008-2010. Among those with claims, 60% of females less than 18 with a severe CHD classification had at least one Medicaid claim with a CHD diagnosis (Table 3c). For almost every other combination of age, sex, and CHD severity, less than approximately 30% of those known to have a CHD had at least one Medicaid claim with a CHD diagnosis during 2008-2010 (Table3c).

Crude Model and Possible Confounders

Outcome 1- a Medicaid Claim during the 2008-2010 surveillance period

Separate logistic regressions were performed with a Medicaid claim from 2008-2010 as the dependent variable and age group, gender, and CHD severity as the exposure variables (see Table 4). An odds ratio (OR) > 1 indicates lack of a Medicaid claim. The crude OR for age was 1.66 (95% CI: 1.39, 1.98) for those 18-24 years, and 1.35 (95% CI: 1.18, 1.54) for those 25-62 years. That is, compared to those who were less than 18 years old, those who were 18-24 and 25-62 years of age were 1.66 and 1.35 times as likely to have not sought care in 2008-2010 surveillance period, respectively. When compared to females, males were less likely to have sought care (OR: 1.02, 95% CI: 0.96, 1.08) during 2008-2010. With respect to CHD severity levels, those classified as *severe* were more likely to have sought care in 2008-2010 than those classified as *Shunts* and those classified as *Valves.* However, those classified as *Shunts + Valves and Other* were less likely to have sought care when compared to those classified as *severe.*

Outcome 2- a CHD-Related Medicaid Claim during the 2008-2010 surveillance period

Among those with a Medicaid claim during 2008-2010, older individuals were also less likely than younger ones to have a CHD diagnosis coded (Table 4). When compared with those < 18 the crude OR was 1.23 (95% CI: 0.93, 1.63) for those 18-24, and 2.69 (95% CI: 2.13, 3.40) for those 26-62. In other words, among persons with a Medicaid claim, compared with those < 18 years of age, the group aged 18-24 was 1.23 times less likely to have a CHD diagnosis and the group aged the 24-62 was 2.69 times less likely to have a CHD diagnosis. Among those with a Medicaid claim, males when compared to females were less likely to have a CHD diagnosis (OR: 1.02, 95% CI: 0.92, 1.13) during 2008-2010. The crude OR for severity was 7.06 (95% CI: 6.10, 8.16) for those classified as *Shunts*, 10.8 (95% CI: 8.90, 13.11) for *Shunts + Valves,* 2.73 (95% CI:

2.04, 3.65) for *Valves, and* 15.06 (95% CI: 11.89, 19.08) for *Other.* That is, when compared to CHD patients who were classified as *severe,* those who had one of the other severity level classification were 3 to 15 times more likely to have had a Medicaid claim without a CHD diagnosis during 2008-2010.

Final Adjusted Model Odds Ratio

Outcome 1- a Medicaid Claim during the 2008-2010 surveillance period

The final adjusted model included the variables age, sex, and CHD severity. Race was not included in this model due to missing values. There was no evidence of collinearity. The chunk test revealed that at least some interaction terms were significant. Therefore, the chunk test was followed by the BWE method. Using the BWE approach, the interactions between age and sex and age and CHD severity were found to be significant (p=<.0001 and p=0.03, respectively).

Below is the final adjusted model:

Logit P (a Medicaid Claim between 2008 and 2010) =

α+β1(age)+β2(sex)+β3(CHD severity)+β4(age*sex)+β5(age*CHD severity)

Goodness of Fit (GOF) was assessed using the Hosmer-Lemeshow (HL) statistic to determine how well the model fits the data. The HL GOF test for this model yielded a χ^2 = 2.034 (p=0.958). There is no evidence that this model does not fit the data well.

Outcome 2- a CHD-Related Medicaid Claim during the 2008-2010 surveillance period

The final adjusted model included the variables age, sex, and CHD severity. Race was not included in this model due to missing values. There was no evidence of collinearity among the variables in the model. While the chunk test found no significant interaction terms, the BWE approach was used to test each interaction term separately.

Results revealed the interactions between age and sex and age and CHD severity were significant (p=0.03 and 0.0002, respectively).

Below is the final adjusted model:

Logit P (a CHD-related Medicaid Claim between 2008-2010) =

$\alpha+\beta1(age)+\beta2(sex)+\beta3(CHD\ severity) + \beta4(age*sex)+ \beta4(age*CHD\ severity)$

Goodness of Fit (GOF) was assessed using the Hosmer-Lemeshow (HL) statistic to determine how well the model fits the data. The HL GOF test for this model yielded a χ^2 = 2.125 (p=0.977). There is no evidence that this model does not fit the data well.

Table 5 summarizes the results of the final adjusted model for each outcome. Interactions between age as of 1/1/2008 and sex, and age as of 1/1/2008 and CHD severity were found to be significant for both outcomes. The variables included in the final adjusted model for each outcome were age as of 1/1/2008, sex, CHD severity, plus the interaction terms between age as of 1/1/2008 and sex, and age as of 1/1/2008 and CHD severity. Generally, when compared to females less than 18 years with a *severe* CHD classification, the odds of not having a Medicaid claim during the 2008-2010 was not significantly greater when compared to the odds of not having a claim during this same period for those in a varied combination of age, sex, and severity groups. However, there were a few exceptions, including males, 18-24 years, with a *Shunts* and *Shunt + Valve* classification. The adjusted OR was 2.83 (95% CI: 1.86, 4.29) and 3.98 (95% CI: 2.64, 6.01), respectively. In regard to outcome 2, when compared to females less than 18 years with a *severe* CHD classification, the odds of having a Medicaid claim without a CHD-related ICD-9-CM diagnostic code during 2008-2010 was greater than the odds of having a claim with a CHD-related diagnostic code during this same period for those in a varied

combination of age, sex, and severity groups. For example, the ORs for models that were statistically significant ranged from 2.86 to 24.32. That is, when compared to females less than 18 years with a *severe* CHD classification, males, 25-62 years with a *severe* CHD classification were 2.86 times more likely to not have a Medicaid claim with a CHD diagnosis, and females, 25-62 years with a *Shunt + Valve* classification were 24.32 times more likely to not have a Medicaid claim with a CHD diagnosis.

Discussion

The aim of this study was to use Medicaid data to determine which CHD patients were more likely to continue to obtain medical care under Medicaid coverage throughout the life course, and among those who had ongoing Medicaid coverage, which CHD patients were more likely to continue care in a specialized care facility (as estimated by the presence of a CHD diagnosis code on a Medicaid claim). Overall, among the CHD patients who resided within the five county catchment area during 1999-2007, approximately half from each age group (<18, 18-24, 25-62 years) continued care as a Medicaid beneficiary during 2008-2010. Among those that continued care, generally less than 30% received care in which Medicaid was billed with a CHD diagnostic code. Other studies using only primary billing codes from administrative datasets found that during a two-month sampling window, approximately 28% adult CHD patients were not identified as having CHD because of the absence of any CHD-related code (60).

We found that among 9-11 year olds, there were more males who had a Medicaid claim during 2008-2010, and among those with claims, more males had a CHD diagnosis on their Medicaid claim compared to females. By ages 12-17, the proportions of males to females were approximately equal. However, after age 18, women made up a larger proportion of Medicaid beneficiaries who received care during the three-year surveillance

period. The results for the outcome of having a Medicaid claim during the 2008-2010 surveillance period supported the hypothesis and findings within the literature that males, older than 18, were less likely to have received Medicaid-paid health care during the 2008-2010 period (11). However, among those who did have Medicaid claims, within each age category (i.e., 18-24 and 25-62), women were more likely to have a Medicaid-paid claim without a CHD diagnosis. These results are supported by how individuals may qualify for Medicaid after the age of 18 years of age. That is, women are more likely than men to qualify for Medicaid after 18 years of age due to pregnancy status (50). It is disturbing that their CHD condition was apparently not noted when they received prenatal care, as specialty care may be indicated. Additionally, these findings are consistent with other data that show that males having a simple shunt lesion compared to a severe lesion were at higher risk of not continuing care (11).

Strengths and Limitations

The strengths of this study include the availability of a large administrative data set that allowed for the capturing of information, including demographics and health seeking behaviors, of adolescent and adult CHD patients over time. Additionally, the sample size in both the1999-2007 and the 2008-2010 periods were large enough to allow for an appropriate analysis. The study was also able to shed light on insurance as a barrier for continuity of care especially for adult males. Several studies looking at the patterns and disparities in insurance coverage over time have found that women tend to have slightly higher insurance rates than men (47, 60). Callahan et al. found that in a population of approximately 12,000 young adults between the ages of 19-24, less than 3% were covered by Medicaid and about one third were uninsured (61) . In contrast, women were less likely

than men to be uninsured and approximately 11% reported being on Medicaid. Although uninsured young adults of both genders were significantly more likely than their counterparts who were privately insured to report delaying or missing healthcare visits or having no contact with a health professional in the previous year, young women with Medicaid did not differ from privately insured women on these measures (61).

A limitation of this study includes the sparse reporting of the race variable. Access to care has been shown to be influenced by race (61), however due to the amount of missing data, race was omitted from all statistical modeling. An additional limitation includes the use of Medicaid as the only data source. It is possible that patients who were classified as not having received care in the 2008-2010 surveillance period could have actually been seen in care during this period, but were covered by a private insurance plan. This issue arises from an inability to effectively crosslink information on the administrative Medicaid data with medical/clinical records from other data sources. Another potential weakness of the study included the exclusion of individuals who resided outside of the five metro-Atlanta counties between 1999 and 2007, but moved into one of the five counties between 2008 and 2010 as well as those who resided inside the five metro-Atlanta counties between 1999 and 2007, but moved out of the five counties between 2008 and 2010. Despite this exclusion, further analyses (see Chapter IV) determined that there were no differences between the aforementioned groups and those that stayed within the five counties during the 12-year period.

Conclusion

This study found that males over the age of 18 regardless of CHD severity were significantly less likely to have a Medicaid-paid claim when compared to females less than 18 years with a severe CHD classification. Among those with a Medicaid claim, the

likelihood of not having a CHD diagnosis for at least one claim during the 2008-2010 surveillance period is equally as high for all age groups, genders, and severity groupings (excluding *Valves*) when compared to females less than 18 years with a severe CHD classification. This study highlights the age-related constraints or pitfalls of the Medicaid program regarding the current eligibility criteria in Georgia. Georgia is one of 23 states not currently implementing the ACA Medicaid expansion, which if implemented could extend Medicaid coverage to nearly 600,0000 low income adults in the state. The present study can be used to inform policy makers in regards to how current Medicaid eligibility criteria may affect continual care among beneficiaries.

References

1. U.S. Department of Health and HumanServices. Congenital Heart Defects. (http://www.nhlbi.nih.gov/health/health-topics/topics/chd)
2. Congenital Heart Public Health Consortium. Congenital Heart Public Health Consortium FAQ Fact Sheet-- Long Version. 2012 1-12 p.(http://www.chphc.org/hostedsites/Documents/CHD_FactSheet-long.pdf)
3. Moons P, Van Deyk K, De Geest S, et al. Is the severity of congenital heart disease associated with the quality of life and perceived health of adult patients? *Heart*. 2005;91(9):1193–8.
4. Congenital Heart Public Health Consortium. Congenital Heart Defects Fact Sheet. 2011;(http://www.chphc.org/hostedsites/Pages/CHDTOOLS-CHD-Fact-Sheet-short.aspx). (Accessed December 12, 2015)
5. van der Bom T, Zomer AC, Zwinderman AH, et al. The changing epidemiology of congenital heart disease. *Nat. Rev. Cardiol.* 2011;8(1):50–60.
6. Oster ME, Riehle-Colarusso T, Simeone RM, et al. Public Health Science Agenda for Congenital Heart Defects: Report From a Centers for Disease Control and Prevention Experts Meeting. *J. Am. Heart Assoc.* 2013;2(5):e000256–e000256.
7. Pages - CHDTOOLS-lifelong-care. (http://www.chphc.org/hostedsites/Pages/CHDTOOLS-lifelong-care.aspx). (Accessed December 12, 2015)
8. Marelli AJ, Ionescu-Ittu R, Mackie AS, et al. Lifetime Prevalence of Congenital Heart Disease in the General Population from 2000 to 2010. *Circulation*. 2014;749–756.

9. Moore JD. SCHIP in the Formative Years: An Update. Washington, DC: 2000.

10. Gurvitz MZ, Inkelas M, Lee M, et al. Changes in hospitalization patterns among patients with congenital heart disease during the transition from adolescence to adulthood. *J. Am. Coll. Cardiol.* 2007;49(8):875–82.

11. Mackie AS, Ionescu-Ittu R, Therrien J, et al. Children and adults with congenital heart disease lost to follow-up: who and when? *Circulation*. 2009;120(4):302–9.

12. National Center of Birth Defects and Developmental Disabilities (NCBDD), Centers for Disease Control and Prevention (CDC). Congenital Heart Defects. (http://www.cdc.gov/ncbddd/heartdefects/research.html). (Accessed February 7, 2016)

13. Surveillance of Congenital Heart Defects Across the Lifespan. (http://acf.hhs.gov/hhsgrantsforecast/index.cfm?switch=grant.view&gff_grants_forecastInfoID=100000437). (Accessed February 7, 2016)

14. Book WM, Hogue C, Raskin-Hood C. Population surveillance data repository for adolescents and adults with congenital heart defects. Atlanta, Ga: 2013 1-14 p.

15. National Center of Birth Defects and Developmental Disabilities, Division of Birth Defects and Developmental Disabilities. Population-Based Surveillance of Congenital Heart Defects among Adolescents and Adults. 2014.(http://www.cdc.gov/ncbddd/heartdefects/documents/chdsurveillance_factsheet_cleared.pdf)

16. John KA. Methodology to Estimate Adolescent and Adult Congenital Heart Defect (CHD) Prevalence in Five Metropolitan Georgia Counties: 2008-2010. 2015.

17. Marelli AJ, Mackie AS, Ionescu-Ittu R, et al. Congenital Heart Disease in the

General Population: Changing Prevalence and Age Distribution. *Circulation*. 2006;115(2):163–172.

18. Goossens E, Stephani I, Hilderson D, et al. Transfer of Adolescents With Congenital Heart Disease From Pediatric Cardiology to Adult Health Care. *J. Am. Coll. Cardiol.* 2011;57(23):2368–74.
19. O'Leary JM, Siddiqi OK, de Ferranti S, et al. The Changing Demographics of Congenital Heart Disease Hospitalizations in the United States, 1998 Through 2010. *JAMA*. 2013;309(10):984–986.
20. Centers for Disease Control and Prevention (CDC). Basics about Diabetes. (http://www.cdc.gov/diabetes/basics/diabetes.html). (Accessed February 21, 2016)
21. Oandansan P. Association of Diabetes Mellitus with Hospitalization among Adult Congenital Heart Defect Patients, 2008-2010. 2015.
22. Simpson G, Bloom B, Cohen R, et al. Access to Health Care Part 1: Children. 1997 1-54 p.
23. Devoe JE, Baez A, Angier H, et al. Barriers to Health Care Access for Low-Income Families. *Ann. Fam. Med.* 2007;5(6):511–518.
24. Fernandes SM, Landzberg MJ. Transitioning the young adult with congenital heart disease for life-long medical care. *Pediatr. Clin. North Am.* 2004;51(6 SPEC. ISS.):1739–1748.
25. Kaiser Foundation. Health Coverage for Low-Income Populations: A Comparison of Medicaid and SCHIP. 2006.
26. Department Of Health And Human Services Centers For Medicare & Medicaid Services Center For Medicaid And State Operations. Medicaid At-a-Glance 2005:

A Medicaid Information Source. *CMS-11024-05*. 2005;11. (https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/Downloads/maag2005.pdf). (Accessed December 11, 2015)

27. Georgia Department of Community Health. Medicaid Eligibility. 2013.(http://dch.georgia.gov/sites/dch.georgia.gov/files/related_files/site_page/MedicaidEligibilityFY14_Final.pdf)
28. The Henry J. Kaiser Family Foundation. The Georgia Health Care Landscape. (http://kff.org/health-reform/fact-sheet/the-georgia-health-care-landscape/). (Accessed February 8, 2016)
29. The Henry J. Kaiser Family Foundation. Medicaid and CHIP Eligibility, Enrollment, Renewal, and Cost-Sharing Policies as of January 2016: Findings from a 50-State Survey. 2016 (Accessed January 25, 2016) 1-74 p.(http://files.kff.org/attachment/report-medicaid-and-chip-eligibility-enrollment-renewal-and-cost-sharing-policies-as-of-january-2016-findings-from-a-50-state-survey). (Accessed January 25, 2016)
30. Georgia Department of Community Health. Medicaid FAQs. (https://dch.georgia.gov/medicaid-faqs#eligibility). (Accessed February 8, 2016)
31. The Henry J. Kaiser Family Foundation. Medicaid Income Eligibility Limits for Infants Ages 0 – 1, 2000-2016. (http://kff.org/medicaid/state-indicator/medicaid-income-eligibility-limits-for-infants-ages-0-1/). (Accessed February 3, 2016)
32. The Henry J. Kaiser Family Foundation. Medicaid Income Eligibility Limits for Children Ages 1 – 5, 2000-2016. (http://kff.org/medicaid/state-indicator/medicaid-

income-eligibility-limits-for-children-ages-1-5/). (Accessed February 8, 2016)

33. The Henry J. Kaiser Family Foundation. Medicaid Income Eligibility Limits for Children Ages 6-18, 2000-2016. (http://kff.org/medicaid/state-indicator/medicaid-income-eligibility-limits-for-children-ages-6-18/). (Accessed February 8, 2016)
34. The Henry J. Kaiser Family Foundation. Medicaid and CHIP Income Eligibility Limits for Pregnant Women, 2003-2016. (http://kff.org/medicaid/state-indicator/medicaid-and-chip-income-eligibility-limits-for-pregnant-women/). (Accessed February 8, 2016)
35. State of Georgia Department of Community Health- Medicaid and PeachCare for Kids Design Strategy Report. 2012.
36. The Henry J. Kaiser Family Foundation. Medicaid Enrollment by Gender. (http://kff.org/medicaid/state-indicator/medicaid-enrollment-by-gender/). (Accessed February 8, 2016)
37. The Henry J. Kaiser Family Foundation. Medicaid Enrollment by Race/Ethnicity. (http://kff.org/medicaid/state-indicator/medicaid-enrollment-by-raceethnicity/). (Accessed February 8, 2016)
38. The Henry J. Kaiser Family Foundation. Medicaid Enrollment by Age. (http://kff.org/medicaid/state-indicator/medicaid-enrollment-by-age/). (Accessed February 8, 2016)
39. The Henry J. Kaiser Family Foundation. Distribution of Medicaid Enrollees by Enrollment Group. (http://kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/). (Accessed February 8, 2016)
40. Cervone A. What's Up With CHIP? (PeachCare) + An Advocacy Ask - Voices for

Georgia's Children – A Nonprofit Child Policy & Advocacy Organization. *Voices Georg. Child. – A Nonprofit Child Policy Advocacy Organ.* 2014;(http://georgiavoices.org/2014/04/whats-chip-childrens-health-insurance-program/). (Accessed December 14, 2015)

41. Georgia | Medicaid.gov. (http://www.medicaid.gov/medicaid-chip-program-information/by-state/georgia.html). (Accessed December 14, 2015)
42. Georgia Department of Community Health. PeachCare For Kids Fact Sheet. 2013;4. (http://dch.georgia.gov/sites/dch.georgia.gov/files/related_files/site_page/PeachCareForKidsFY14_Final.pdf). (Accessed December 11, 2015)
43. The Henry J. Kaiser Family Foundation. Separate Children's Health Insurance Program (CHIP) Income Eligibility Limits for Children, 2000-2016. (http://kff.org/medicaid/state-indicator/separate-childrens-health-insurance-program-chip-income-eligibility-limits-for-children/). (Accessed February 8, 2016)
44. The Henry J. Kaiser Family Foundation. Total Number of Children Ever Enrolled in CHIP Annually. (http://kff.org/other/state-indicator/annual-chip-enrollment/#graph). (Accessed February 8, 2016)
45. The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update. 2016 (Accessed January 25, 2016) 1-10 p.(https://kaiserfamilyfoundation.files.wordpress.com/2016/01/8659-04-the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid.pdf). (Accessed January 25, 2016)
46. Georgians for a Healthy Future and Georgia Budget & Policy Institute.

Demographics of Georgians in the Coverage Gap – Georgians for a Healthy Future. 2015;(http://healthyfuturega.org/ghf_resource/demographics-of-georgians-in-the-coverage-gap/). (Accessed February 8, 2016)

47. Adams SH, Newacheck PW, Park MJ, et al. Health insurance across vulnerable ages: patterns and disparities from adolescence to the early 30s. *Pediatrics* [electronic article]. 2007;119(5):e1033–9. (http://pediatrics.aappublications.org/content/119/5/e1033.abstract). (Accessed January 31, 2016)

48. The Henry J. Kaiser Family Foundation. Lack of Coverage: A Long Term Problem for Most Uninsured. (https://kaiserfamilyfoundation.files.wordpress.com/2013/01/lack-of-coverage-a-long-term-problem-for-most-uninsured.pdf). (Accessed February 8, 2016)

49. The Henry J. Kaiser Family Foundation. Medicaid Financial Eligibility: Primary Pathways for the Elderly and People with Disabilities. 2010 (Accessed January 26, 2016) 1-9 p.(https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8048.pdf). (Accessed January 26, 2016)

50. The Henry J. Kaiser Family Foundation. The Affordable Care Act's Impact on Medicaid Eligibility, Enrollment, and Benefits for People with Disabilities. 2014 (Accessed January 25, 2016) 1-18 p.(https://kaiserfamilyfoundation.files.wordpress.com/2014/04/8390-02-the-affordable-care-acts-impact-on-medicaid-eligibility.pdf). (Accessed January 25, 2016)

51. Laurence B. What Is the Difference Between Social Security Disability (SSDI) and SSI? (http://www.disabilitysecrets.com/page5-13.html). (Accessed February 9, 2016)

52. Financial Eligibility for SSI . (http://www.disabilitysecrets.com/topics/financial-eligibility-ssi.htm). (Accessed February 9, 2016)

53. Linebaugh M. Getting SSI Disability Benefits for a Child With a Congenital Heart Defect. (http://www.disabilitysecrets.com/resources/disability/child-disability/getting-ssi-disability-benefi). (Accessed January 30, 2016)

54. Linebaugh M. Congenital Heart Disease: When Are Disability Benefits Available? (http://www.disabilitysecrets.com/resources/social-security-disability-coverage/congenital-heart-disease.htm). (Accessed February 1, 2016)

55. Laurence B. Income Limits & SSI Disability Eligibility. (http://www.disabilitysecrets.com/resources/social-security-disability/supplemental-security-income-ssi/income-limits-eligibility.htm). (Accessed February 9, 2016)

56. Netter L. Disability Benefits for Children. (http://www.disabilitysecrets.com/page6-4.html). (Accessed February 2, 2016)

57. Netter L. When a Child Receiving SSI Disability Becomes an Adult: Age 18 Redeterminations | Disability Secrets. (http://www.disabilitysecrets.com/resources/disability/when-a-child-receiving-ssi-disability-becomes-). (Accessed February 2, 2016)

58. Hemmeter J, Gilby E. THE AGE-18 REDETERMINATION AND POSTREDETERMINATION PARTICIPATION IN SSI. *Soc. Secur. Bull.*

2009;69(4).

59. Gurvitz M, Valente AM, Broberg C, et al. Prevalence and Predictors of Gaps in Care Among Adult Congenital Heart Disease Patients (The Health, Education and Access Research Trial: HEART-ACHD). *J. Am. Coll. Cardiol.* 2013;

60. Broberg C, McLarry J, Mitchell J, et al. Accuracy of Administrative Data for Detection and Categorization of Adult Congenital Heart Disease Patients from an Electronic Medical Record. *Pediatr. Cardiol.* 2015;36(4):719–725.

61. Callahan ST, Cooper WO. Uninsurance and health care access among young adults in the United States. *Pediatrics*. 2005;116(1):88–95.

62. M. N, G. W, D. D, et al. Prevalence and patterns of retention in cardiac care in young adults with congenital heart disease. *J. Am. Coll. Cardiol.* [electronic article]. 2011;57(14):E464. (http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L70400141\nhttp://dx.doi.org/10.1016/S0735-1097(11)60464-6\nhttp://elvis.ubvu.vu.nl:9003/vulink?sid=EMBASE&issn=07351097&id=doi:10.1016%2FS0735-1097%2811%2960464-6&atitle=Prevalence+)

TABLES

Table 1. Case Definition for Surveillance of CHD, Emory-CDC Pilot Project

seen at one of the GA healthcare facilities that contributed data **OR** had a GA Medicaid claim between 2008-2010 **AND**
had at least one ICD-9-CM CHD-related code during this period **AND**
was at least 11 years of age and less than 65 years of age as of 01/01/2010 **AND**
was alive as of 01/01/2010 **AND**
resided in GA

Table 2a. Demographics for CHD Medicaid Patients^ by Catchment Area Residence and Healthcare Seeking Behavior in 2008-2010

			2008 - 2010						
	Total Population *(n=5,944)*		**Resides within five counties[*] and seen in care *(n=2,735)***		**Resides outside five counties [**] and seen in care *(n=659)***		**Not seen in care *(n=2,550)***		**X^{2+}**
	Frequency (n)	%[++]	Frequency (n)	%[++]	Frequency (n)	%[++]	Frequency (n)	%[++]	
9-11	1,831	30.8	752	27.5	157	23.8	922	36.2	
Sex									
Male	965	52.7	390	51.9	79	50.3	496	53.8	
Female	866	47.3	362	48.1	78	49.7	426	46.2	ns
Race									
White	324	17.7	176	23.4	73	46.5	75	8.1	
Black	516	28.2	381	50.7	56	35.7	79	8.6	
Other	23	1.3	19	2.5	2	1.3	2	0.2	
Unknown	968	52.9	176	23.4	26	16.7	766	83.1	
12-13	465	7.8	252	9.2	59	9.0	154	6.0	
Sex									
Male	234	50.3	134	53.2	27	45.8	73	47.4	
Female	231	49.7	118	46.8	32	54.4	81	52.6	ns
Race									
White	108	23.2	54	21.4	23	39	31	20.1	
Black	192	41.3	142	56.4	20	33.9	30	19.5	
Other	5	1.1	3	1.2	1	1.7	1	0.7	
Unknown	160	34.4	53	21	15	25.4	92	59.7	
14-17	620	10.4	369	13.5	71	10.8	180	7.1	
Sex									
Male	316	51	198	53.7	32	45.1	86	47.8	
Female	304	49	171	46.3	39	54.9	94	52.2	ns
Race									
White	111	17.9	48	13	33	46.5	30	16.7	
Black	192	41.3	213	57.7	27	38	53	29.4	
Other	5	1.1	11	3	1	1.4	1	0.6	
Unknown	160	34.4	97	26.3	10	14.1	96	53.3	
18-24	833	14	350	12.8	96	14.6	387	15.2	
Sex									
Male	383	46	127	36.3	43	44.8	213	55	26.0
Female	450	54	223	63.7	53	55.2	174	45	(<.0001)
Race									
White	198	23.8	83	23.7	42	43.8	73	18.9	
Black	407	48.9	218	62.3	44	45.8	145	37.5	
Other	13	1.6	9	2.6	0	0	4	1	
Unknown	215	25.8	40	11.4	10	10.4	165	42.6	
25-62	2,195	36.9	1,012	37	276	41.9	907	35.6	
Sex									
Male	584	27.1	256	25.3	73	26.5	265	29.2	
Female	1,601	72.9	756	74.7	203	73.5	642	70.8	3.7 (.05)
Race									
White	547	24.9	240	23.7	143	51.8	164	18.1	
Black	1,054	48	645	63.7	108	39.1	301	33.2	
Other	44	2	29	2.9	5	1.8	10	1.1	
Unknown	550	25.1	98	9.7	20	7.3	432	47.6	

* Resides within the five Metro-Atlanta counties at any time during 2008-2010;

** Resides outside the five Metro-Atlanta counties at any time during 2008-2010;

[+] X^2 test of proportions for sex among those residing within the five county areas and seen in care between 2008 and 2010 vs those not seen in care between 2008 and 2010

[++]: Percentages within subcategories

Table 2b. Severity of CHD among Medicaid Patients* by Catchment Area Residence and Healthcare Seeking Behavior in 2008-2010

	Total Population *(n=5,944)*		2008 - 2010 Resides within the five counties* and seen in care *(n=2,735)*		Resides outside the five counties** and seen in care *(n=659)*		Not seen in care *(n=2,550)*		X^{2+}
	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++	
Age (years) as of 1/1/2008									
9-11	1,831	30.8	752	27.5	157	23.8	922	36.2	
Severity Group									
Severe	201	11.0	90	12.0	18	11.5	93	10.1	ns
Shunts	997	54.5	376	50.0	88	56.1	533	57.8	
Shunts + Valves	338	18.5	161	21.4	31	19.8	146	15.8	
Valves	32	1.8	12	1.6	4	2.6	16	1.70	
Other	263	14.4	113	15.0	16	10.2	134	14.5	
12-13	465	7.8	252	9.2	59	9.0	154	6.0	
Severity Group									
Severe	112	24.1	66	26.2	14	23.7	32	20.8	ns
Shunts	182	39.1	96	38.1	20	33.9	66	42.9	
Shunts + Valves	98	21.1	48	19.1	16	27.1	34	22.1	
Valves	13	2.8	8	3.2	1	1.7	4	2.60	
Other	60	12.9	34	13.5	8	13.6	18	11.7	
14-17	620	10.4	369	13.5	71	10.8	180	7.1	
Severity Group									
Severe	122	19.7	70	19.0	11	15.5	41	22.8	ns
Shunts	201	32.4	119	32.3	26	36.6	56	31.1	
Shunts + Valves	178	28.7	106	28.7	19	26.8	53	29.4	
Valves	9	1.5	6	1.6	1	1.4	2	1.10	
Other	110	17.7	68	18.4	14	19.7	28	15.6	
18-24	833	14	350	12.8	96	14.6	387	15.2	
Severity Group									
Severe	146	17.5	82	23.4	10	10.4	54	14.0	19.8
Shunts	233	28.0	97	27.7	26	27.1	110	28.4	.0006
Shunts + Valves	258	31.0	81	23.1	39	40.6	138	35.7	
Valves	10	1.2	3	0.9	4	4.2	3	0.8	
Other	186	22.3	87	24.9	17	17.7	82	21.2	
25-62	2,195	36.9	1,012	37	276	41.9	907	35.6	
Severity Group									
Severe	198	9.0	88	8.7	26	9.4	84	9.3	ns
Shunts	369	16.8	177	17.5	42	15.2	150	16.5	
Shunts + Valves	836	38.1	388	38.3	103	37.3	345	38.0	
Valves	10	0.5	6	0.6	0	0.0	4	0.4	
Other	782	35.6	353	34.9	105	38.0	324	35.7	

* Resides within the five metro-Atlanta counties at any time during 2008-2010;

** Resides outside the five Metro-Atlanta counties at any time during 2008-2010;

+ X^2 test of proportions for severity among those residing within the five county areas and seen in care during 2008-2010 vs those not seen in care during 2008- 2010.

++: Percentages within subcategories

Table 2c. Severity of CHD by Age and Sex among Medicaid Patients* by Catchment Area Residence and Healthcare Seeking Behavior in 2008-2010

	Total Population[+] *(n=5,944)*		**Resides within the 5 counties[*] and seen in care** *(n=2,735)*		**Not seen in care** *(n=2,550)*	
	Frequency (n)	%[++]	Frequency (n)	%[++]	Frequency (n)	%[++]
Age (years) as of 1/1/2008						
<18	2,916	49.1	1,373	50.2	1,256	49.3
Male	1,515	52	722	52.6	655	57.8
Severe	221	14.6	111	15.4	87	13.3
Shunts	710	46.9	309	42.8	340	51.9
Shunts + Valves	310	20.5	161	22.3	115	17.6
Valves	26	1.7	14	1.9	11	1.7
Other	248	16.4	127	17.6	102	15.6
Female	1,401	48.0	651	47.4	601	42.4
Severe	214	15.3	115	17.7	79	13.1
Shunts	670	47.8	282	43.3	315	52.4
Shunts + Valves	304	21.7	154	23.7	118	19.6
Valves	28	2.0	12	1.8	11	1.8
Other	185	13.2	88	13.5	78	13.0
18-24	833	14.0	350	12.8	387	15.2
Male	383	46.0	127	36.3	213	18.8
Severe	67	17.5	35	27.6	25	11.7
Shunts	98	25.6	32	25.2	54	25.4
Shunts + Valves	131	34.2	29	22.8	84	39.4
Valves	2	0.5	0	0.0	1	0.5
Other	85	22.2	31	24.4	49	23.0
Female	450	54.0	223	63.7	174	12.3
Severe	79	17.6	47	21.1	29	16.7
Shunts	135	30.0	65	29.2	56	32.2
Shunts + Valves	127	28.2	52	23.3	54	31.0
Valves	8	1.8	3	1.4	2	1.2
Other	101	22.4	56	25.1	33	19.0
25-62	2,195	36.9	1,012	37.0	907	35.6
Male	594	27.1	256	25.3	265	23.4
Severe	47	7.9	18	7.0	21	7.9
Shunts	92	15.5	48	18.8	33	12.5
Shunts + Valves	213	35.9	88	34.4	102	38.5
Valves	2	0.3	1	0.4	1	0.4
Other	240	40.4	101	39.5	108	40.8
Female	1,601	72.9	756	74.7	642	45.3
Severe	151	9.4	70	9.3	63	9.8
Shunts	277	17.3	129	17.1	117	18.2
Shunts + Valves	623	38.9	300	39.7	243	37.9
Valves	8	0.5	5	0.7	3	0.5
Other	542	33.9	252	33.3	216	33.6

* Resides within the five metro-Atlanta counties at any time during 2008-2010;

[+] Georgia Medicaid beneficiaries residing in the five metro-Atlanta counties that had CHD diagnosis between 1999-2008 and age 9-62 as of 1/1/2008

[++]: Percentages within subcategories

Table 3a. Demographics for CHD Medicaid Patients Residing Within the Catchment Area Who Sought Care in 2008-2010 With or Without a CHD Medicaid Claim in 2008-2010

			2008 – 2010						
	Not seen in care* *(n=2,550)*		**Total seen in care & resides in 5 counties *(n=2,735)***		**Seen in care w/CHD dx & resides in 5 counties *(n=522)***		**Seen in care w/o CHD dx & resides in 5 counties *(n=2,213)***		**X^{2+}**
	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++	
Age (years) as of 1/1/2008									
9-11	922	36.2	752	27.5	122	23.4	630	28.5	
Sex									
Male	496	53.8	390	51.9	62	50.8	328	52.1	
Female	426	46.2	362	48.1	60	49.2	302	47.9	ns
Race									
White	75	8.1	176	23.4	31	25.4	145	23.0	
Black	79	8.6	381	50.7	48	39.3	333	52.9	
Other	2	0.2	19	2.5	7	5.7	12	1.9	
Unknown	766	83.1	176	23.4	36	29.5	140	22.2	
12-13	154	6.0	252	9.2	84	16.1	168	7.6	
Sex									
Male	73	47.4	134	53.2	44	52.4	90	53.6	
Female	81	52.6	118	46.8	40	47.6	78	46.4	ns
Race									
White	31	20.1	54	21.4	21	25.0	33	19.6	
Black	30	19.5	142	56.4	39	46.4	103	61.3	
Other	1	0.7	3	1.2	1	1.2	2	1.2	
Unknown	92	59.7	53	21.0	23	27.4	30	17.9	
14-17	180	7.1	369	13.5	107	20.5	262	11.8	
Sex									
Male	86	47.8	198	53.7	51	47.7	147	56.1	
Female	94	52.2	171	46.3	56	52.3	115	43.9	ns
Race									
White	30	16.7	48	13.0	15	14.0	33	12.6	
Black	53	29.4	213	57.7	57	53.3	156	59.5	
Other	1	0.6	11	2.9	2	1.9	9	3.4	
Unknown	96	53.3	97	26.3	33	30.8	64	24.4	
18-24	387	15.2	350	12.8	83	15.9	267	12.1	
Sex									
Male	213	55.0	127	36.3	36	43.4	91	34.1	ns
Female	174	45.0	223	63.7	47	56.6	176	65.9	
Race									
White	73	18.9	83	23.7	21	25.3	62	23.2	
Black	145	37.5	218	62.3	46	55.4	172	64.4	
Other	4	1.0	9	2.6	3	3.6	6	2.3	
Unknown	165	42.6	40	11.4	13	15.7	27	10.1	
25-62	907	35.6	1,012	37.0	126	24.1	886	40.0	
Sex									
Male	265	29.2	256	25.3	43	34.1	213	24.0	
Female	642	70.8	756	74.7	83	65.9	673	76.0	5.9 (.01)
Race									
White	164	18.1	240	23.7	34	27.0	206	23.3	
Black	301	33.2	645	63.7	68	54.0	577	65.1	
Other	10	1.1	29	2.9	5	4.0	24	2.7	
Unknown	432	47.6	98	9.7	19	15.1	79	8.9	

* Not Medicaid claim in 2008-2010+ Chi-Square test for association between those residing within the five counties and sought care during 2008-2010 with or without a CHD diagnosis and sex

++: Percentages within subcategories

Table 3b Severity of CHD among Medicaid Patients Residing Within the Catchment Area with a CHD Medicaid Claim during 1999-2007 and Sought Care in 2008-2010

	2008 - 2010								
	Not seen in care* *(n=2,550)*		**Total seen in care & resides in 5 counties *(n=2,735)***		**Seen in care with CHD dx and reside within 5 counties (*n=522)***		**Seen in care with no CHD diagnosis and reside within 5 counties *(2,213)***		**X^{2+}**
	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++	
9-11	922	36.2	752	27.5	122	23.4	630	28.5	
Severity Group									143.603
Severe	93	10.1	90	11.9	48	39.3	42	6.7	(<.0001)
Shunts	533	57.8	376	50.0	44	36.1	332	52.6	
Shunt+Valve	146	15.8	161	21.4	16	13.1	145	23.0	
Valve	16	1.7	12	1.6	9	7.4	3	0.5	
Other	134	14.5	113	15.0	5	4.1	108	17.1	
12-13	154	6.0	252	9.2	84	16.1	168	7.6	
Severity Group									36.4344
Severe	32	20.8	66	26.2	41	48.8	25	14.9	(<.0001)
Shunts	66	42.9	96	38.1	23	27.4	73	43.5	
Shunt+Valve	34	22.1	48	19.1	13	15.5	35	20.8	
Valve	4	2.6	8	3.2	3	3.6	5	3.0	
Other	18	11.7	34	13.5	4	4.8	30	17.9	
14-17	180	7.1	369	13.5	107	20.5	262	11.8	
Severity Group									43.1515
Severe	41	22.8	70	18.9	42	39.3	28	10.7	(<.0001)
Shunts	56	31.1	119	32.3	32	29.9	87	33.2	
Shunt+Valve	53	29.4	106	28.7	21	19.6	85	32.4	
Valve	2	1.1	6	1.6	1	0.9	5	1.9	
Other	28	15.6	68	18.4	11	10.3	57	21.8	
18-24	387	15.2	350	12.8	83	15.9	267	12.1	
Severity Group									
Severe	54	14.0	82	23.4	41	49.4	41	15.4	50.8397
Shunts	110	28.4	97	27.7	22	26.5	75	28.1	(<.0001)
Shunt+Valve	138	35.7	81	23.1	11	13.3	70	26.2	
Valve	3	0.8	3	0.9	2	2.4	1	0.4	
Other	82	21.2	87	24.9	7	8.4	80	29.9	
25-62	907	35.6	1,012	37.0	126	24.1	886	40.0	
Severity Group									73.6482 (<.0001)
Severe	84	9.3	88	8.7	23	18.3	65	7.3	
Shunts	150	16.5	177	17.5	44	34.9	133	15.0	
Shunt+Valve	345	38.0	388	38.3	27	21.4	361	40.7	
Valve	4	0.4	6	0.6	4	3.2	2	0.2	
Other	324	35.7	353	34.8	28	22.2	325	36.7	

* Not Medicaid claim in 2008-2010

\+ Chi-Square test for association between those residing within the five counties and sought care during 2008-2010 with or without a CHD diagnosis and sex

++: Percentages within subcategories

Table 3c. Severity of CHD by Age and Sex among Medicaid Patients Residing Within the Catchment Area with a CHD Medicaid Claim during 1999-2007 and Sought Care in 2008-2010

	Not seen in care* *(n=2,550)*		**Resides within the 5 counties* and seen in care *(n=2,735)***		**Seen in care with CHD diagnosis and reside within 5 county area *(n=522)***		**Seen in care with no CHD diagnosis and reside within 5 county area *(n=2,213)***	
	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++	Frequency (n)	%++
Age (years) as of 1/1/2008								
<18	1,256	49.3	1,373	50.2	313	60	1,060	47.9
Male	655	52.2	722	52.6	157	50.2	565	53.3
Severe	87	13.3	111	15.4	62	39.5	49	8.7
Shunts	340	51.9	309	42.8	51	32.5	258	45.7
Shunts + Valves	115	17.6	161	22.3	26	16.6	135	23.9
Valves	11	1.7	14	1.9	7	4.5	7	1.2
Other	102	15.6	127	17.6	11	7.0	116	20.5
Female	601	47.9	651	47.4	156	49.8	495	46.7
Severe	79	13.1	115	17.7	69	44.2	46	9.3
Shunts	315	52.4	282	43.3	48	30.8	234	47.3
Shunts + Valves	118	19.6	154	23.7	24	15.4	130	26.3
Valves	11	1.8	12	1.8	6	3.9	6	1.2
Other	78	13.0	88	13.5	9	5.8	79	16.0
18-24	387	15.2	350	12.8	83	15.9	267	12.1
Male	213	55.0	127	36.3	36	43.4	91	34.1
Severe	25	11.7	35	27.6	20	55.6	15	16.5
Shunts	54	25.4	32	25.2	7	19.4	25	27.5
Shunts + Valves	84	39.4	29	22.8	5	13.9	24	26.4
Valves	1	0.5	0	0.0	0	0.0	0	0.0
Other	49	23.0	31	24.4	4	11.1	27	29.7
Female	174	45.0	223	63.7	47	56.6	176	65.9
Severe	29	16.7	47	21.1	21	44.7	26	14.8
Shunts	56	32.2	65	29.2	15	31.9	50	28.4
Shunts + Valves	54	31.0	52	23.3	6	12.8	46	26.1
Valves	2	1.2	3	1.4	2	4.3	1	0.6
Other	33	19.0	56	25.1	3	6.4	53	30.1
25-62	907	35.6	1,012	37.0	126	24.1	886	40.0
Male	265	29.2	256	25.3	43	34.1	213	24.0
Severe	21	7.9	18	7.0	8	18.6	10	4.7
Shunts	33	12.5	48	18.8	18	41.9	30	14.1
Shunts + Valves	102	38.5	88	34.4	6	14.0	82	38.5
Valves	1	0.4	1	0.4	1	2.3	0	0.0
Other	108	40.8	101	39.5	10	23.3	91	42.7
Female	642	70.8	756	74.7	83	65.9	673	75.9
Severe	63	9.8	70	9.3	15	18.1	55	8.2
Shunts	117	18.2	129	17.1	26	31.3	103	15.3
Shunts + Valves	243	37.9	300	39.7	21	25.3	279	41.5
Valves	3	0.5	5	0.7	3	3.6	2	0.3
Other	216	33.6	252	33.3	18	21.7	234	34.8

* Not Medicaid claim in 2008-2010
++: Percentages within subcategories

Table 4. Crude Odds Ratios for Age Association with Each Outcome

	OR	95% CI	
Outcome 1*			
AGE			
< 18	1.00	---	---
18-24	1.66	1.39	1.98
25-62	1.35	1.18	1.54
Sex			
Female	1.00	---	---
Male	1.02	0.96	1.08
CHD severity			
Severe	1.00	---	---
Shunts	0.86	0.78	0.96
Shunts +Valves	1.00	0.89	1.12
Valve	0.80	0.64	0.99
Other	1.14	1.01	1.29
Outcome 2*			
AGE			
< 18	1.00	---	---
18-24	1.23	0.93	1.63
25-62	2.69	2.13	3.40
Sex			
Female	1.00	---	---
Male	1.02	0.92	1.23
CHD severity			
Severe	1.00	---	---
Shunts	7.06	6.10	8.16
Shunts +Valves	10.80	8.90	13.11
Valve	2.73	2.04	3.65
Other	15.06	11.89	19.08

* *Outcome 1- a Medicaid Claim during 2008-2010 surveillance period;*
** *Outcome 2- a CHD-related Medicaid Claim during 2008-2010 surveillance period*

Table 5. Adjusted Odds Ratio for Each Outcome

CHD Severity

	Severe			*Shunts*			*Shunts +Valves*			*Valves*			*Other*		
	OR	**95%CI**		**OR**	**95% CI**		**OR**	**95% CI**		**OR**	**95% CI**		**OR**	**95% CI**	
Outcome 1															
Female <18	1.00	--	--	1.19	0.90	1.58	1.01	0.74	1.39	1.24	0.61	2.52	1.09	0.77	1.54
Male <18	0.94	0.77	1.15	1.11	0.79	1.58	0.95	0.65	1.38	1.16	0.56	2.42	1.02	0.70	1.51
Female 18-24	0.74	0.47	1.17	1.33	0.89	1.97	**1.87**	**1.25**	**2.80**	1.41	0.27	7.23	1.05	0.68	1.60
Male 18-24	1.58	1.00	2.50	**2.83**	**1.86**	**4.29**	**3.98**	**2.64**	**6.01**	3.00	0.57	15.7	**2.23**	**1.45**	**3.43**
Female 25-62	1.45	0.98	2.16	1.28	0.92	1.80	1.34	1.00	1.81	1.02	0.28	3.71	**1.37**	**1.02**	**1.86**
Male 25-62	**1.77**	**1.16**	**2.70**	**1.56**	**1.08**	**2.26**	**1.64**	**1.18**	**2.27**	1.24	0.34	4.56	**1.67**	**1.21**	**2.32**
Outcome 2															
Female <18	1.00	--	--	**5.29**	**3.60**	**7.78**	**5.92**	**3.82**	**9.17**	2.21	0.86	5.67	**10.36**	**5.89**	**18.23**
Male <18	1.11	0.81	1.50	**5.85**	**3.58**	**9.56**	**6.54**	**3.82**	**11.19**	2.44	0.91	6.51	**11.46**	**6.12**	**21.45**
Female 18-24	**1.84**	**1.01**	**3.33**	**6.09**	**3.29**	**11.28**	**11.53**	**5.42**	**24.53**	0.78	0.07	8.81	**20.74**	**8.65**	**49.71**
Male 18-24	1.26	0.67	2.36	**4.17**	**2.12**	**8.17**	**7.89**	**3.60**	**17.29**	0.53	0.04	6.41	**14.18**	**5.78**	**34.79**
Female 25-62	**5.01**	**2.77**	**9.05**	**5.58**	**3.40**	**9.17**	**24.32**	**14.30**	**41.35**	0.85	0.15	4.83	**21.89**	**12.82**	**37.39**
Male 25-62	2.86	1.48	5.55	3.19	1.83	5.56	13.90	7.73	25.01	**0.49**	**0.08**	**2.87**	12.51	7.07	22.14

* *Outcome 1- a Medicaid Claim during 2008-2010 surveillance period;*
** *Outcome 2- a CHD-related Medicaid Claim during 2008-2010 surveillance period.*

Note: Significant Odds Ratios are bolded.

Supplementary Table 1. CHD-Diagnosed Patients Who Resided Within Catchment Area in 1999-2007 and Who Resided Within the Catchment Area and Sought Care Any Time during 2008-2010

	2008-2010				
	Resides within the 5 counties[*] and seen in care *(n=2,735)*		**Resides within the 5 counties[**] and seen in care** *(n=149)*		**X^{2+}**
	Frequency (n)	%[++]	**Frequency (n)**	%[++]	
Age (years) as of 1/1/2008					
9-11	752	27.5	48	32.2	
Sex					
Male	390	51.9	25	52.1	ns
Female	362	48.1	23	47.9	
Race					
White	176	23.4	22	45.8	
Black	381	50.7	17	35.4	
Other	19	2.5	0	0.0	
Unknown	176	23.4	9	18.8	
Severity Group					
Severe	90	11.9	6	12.5	17.7265
Shunts	376	50	24	50.0	(.001)
Shunts + Valves	161	21.4	7	14.6	
Valve	12	1.6	5	10.4	
Other	113	15.0	6	12.5	
12-13	252	9.2	14	9.4	
Sex					
Male	134	53.2	9	64.3	ns
Female	118	46.8	5	35.7	
Race					
White	54	21.4	6	42.9	
Black	142	56.4	4	28.6	
Other	3	1.2	1	7.1	
Unknown	53	21	3	21.4	
Severity Group					
Severe	66	26.19	2	14.3	ns
Shunts	96	38.1	5	35.7	
Shunts + Valves	48	19.05	4	28.6	
Valve	8	3.17	0	0.0	
Other	34	13.49	3	21.4	
14-17	369	13.5	22	14.8	
Sex					
Male	198	53.7	9	40.9	ns
Female	171	46.3	13	59.1	
Race					
White	48	13	9	40.9	
Black	213	57.7	9	40.9	
Other	11	3	1	4.6	
Unknown	97	26.3	3	13.6	
Severity Group					
Severe	70	18.97	3	13.6	ns
Shunts	119	32.25	7	31.8	
Shunts + Valves	106	28.73	8	36.4	
Valve	6	1.63	0	0.0	
Other	68	18.43	4	18.2	

	2008-2010				
	Resides within the 5 counties[*] and seen in care *(n=2,735)*		**Resides within the 5 counties[**] and seen in care** *(n=149)*		**X^{2+}**
	Frequency (n)	%[++]	**Frequency (n)**	%[++]	
18-24	350	12.8	18	12.1	
Sex					
Male	127	36.3	3	16.7	ns
Female	223	63.7	15	83.3	
Race					
White	83	23.7	8	44.4	
Black	218	62.3	6	33.3	
Other	9	2.6	2	11.1	
Unknown	40	11.4	2	11.1	
Severity Group					
Severe	82	23.4	1	5.6	ns
Shunts	97	27.7	8	44.4	
Shunts + Valves	81	23.1	6	33.3	
Valve	3	0.9	0	0.0	
Other	87	24.9	3	16.7	
25-62	1,012	37	47	31.5	
Sex					
Male	256	25.3	11	23.4	ns
Female	756	74.7	36	76.6	
Race					
White	240	23.7	21	44.7	
Black	645	63.7	23	48.9	
Other	29	2.9	0	0.0	
Unknown	98	9.7	3	6.4	
Severity Group					
Severe	88	8.7	3	6.4	ns
Shunts	177	17.5	14	29.8	
Shunts + Valves	388	38.3	14	29.8	
Valve	6	0.6	0	0.0	
Other	353	34.9	16	34.0	

* Resides within the Metro Atlanta five county area (Clayton, Cobb, Dekalb, Fulton, and Gwinnett) at any point during 1999-2007 and 2008-2010

** Resides outside the Metro Atlanta five county area (Clayton, Cobb, Dekalb, Fulton, and Gwinnett) during 1999-2007 and moved into one of the 5 county areas between 2008 and 2010

[++]: Percentages within subcategories

Supplementary Table 2. CHD-Diagnosed Patients Who Reside Inside or Outside Catchment Area in 1999-2007 and Who Reside Within the Catchment Area and Sought Care Any Time during 2008-2010

	2008-2010				
	Resides outside 5 counties[*] and seen in care *(n=659)*		**Resides within 5 counties** and seen in care *(n=149)***		**X^2**
	Frequency (n)	%[++]	**Frequency (n)**	%[++]	
Age (years) as of 1/1/2008					
9-11	157	23.8	48	32.2	
Sex					
Male	79	50.3	25	52.1	ns
Female	78	49.7	23	47.9	
Race					
White	73	46.5	22	45.8	
African American	56	35.7	17	35.4	
Other	2	1.3	0	0.0	
Unknown	26	16.7	9	18.8	
Severity Group					
Severe	18	11.5	6	12.5	
Shunts	88	56.1	24	50.0	ns
Shunts + Valves	31	19.8	7	14.6	
Valve	4	2.6	5	10.4	
Other	16	10.2	6	12.5	
12-13	59	9.0	14	9.4	
Sex					ns
Male	27	45.8	9	64.3	
Female	32	54.4	5	35.7	
Race					
White	23	39.0	6	42.9	
African American	20	33.9	4	28.6	
Other	1	1.7	1	7.1	
Unknown	15	25.4	3	21.4	
Severity Group					
Severe	14	23.7	2	14.3	
Shunts	20	33.9	5	35.7	ns
Shunts + Valves	16	27.1	4	28.6	
Valve	1	1.7	0	0.0	
Other	8	13.6	3	21.4	
14-17	71	10.8	22	14.8	
Sex					
Male	32	45.1	9	40.9	ns
Female	39	54.9	13	59.1	
Race					
White	33	46.5	9	40.9	
African American	27	38.0	9	40.9	
Other	1	1.4	1	4.6	
Unknown	10	14.1	3	13.6	
Severity Group					
Severe	11	15.5	3	13.6	ns
Shunts	26	36.6	7	31.8	
Shunt & Valve	19	26.8	8	36.4	
Valve	1	1.4	0	0.0	
Other	14	19.7	4	18.2	

	2008-2010				
	Resides outside 5 counties* and seen in care *(n=659)*		**Resides within 5 counties** and seen in care *(n=149)***		**X^2**
	Frequency (n)	%++	**Frequency (n)**	%++	
18-24	96	14.6	18	12.1	
Sex					
Male	43	44.8	3	16.7	4.9816
Female	53	55.2	15	83.3	(.03)
Race					
White	42	43.8	8	44.4	
African American	44	45.8	6	33.3	
Other	0	0.0	2	11.1	
Unknown	10	10.4	2	11.1	
Severity Group					
Severe	10	10.4	1	5.6	ns
Shunts	26	27.1	8	44.4	
Shunts + Valves	39	40.6	6	33.3	
Valve	4	4.2	0	0.0	
Other	17	17.7	3	16.7	
25-62	276	41.9	47	31.5	
Sex					
Male	73	26.5	11	23.4	ns
Female	203	73.5	36	76.6	
Race					
White	143	51.8	21	44.7	
African American	108	39.1	23	48.9	
Other	5	1.8	0	0.0	
Unknown	20	7.3	3	6.4	
Severity Group					
Severe	26	9.4	3	6.4	ns
Shunts	42	15.2	14	29.8	
Shunts + Valves	103	37.3	14	29.8	
Valve	0	0.0	0	0.0	
Other	105	38.0	16	34.0	

* Resides within the Metro Atlanta five county area (Clayton, Cobb, DeKalb, Fulton, and Gwinnett) at any point during 1999-2007 and moved out of the five county areas between 2008 and 2010;
** Resides outside the Metro Atlanta five county area (Clayton, Cobb, DeKalb, Fulton, and Gwinnett) during 1999-2007 and moved into one of the five county areas between 2008 and 2010
++: Percentages within subcategories

Supplementary Table 3. Adjusted Odds Ratio for Each Outcome for the Main Effect Age

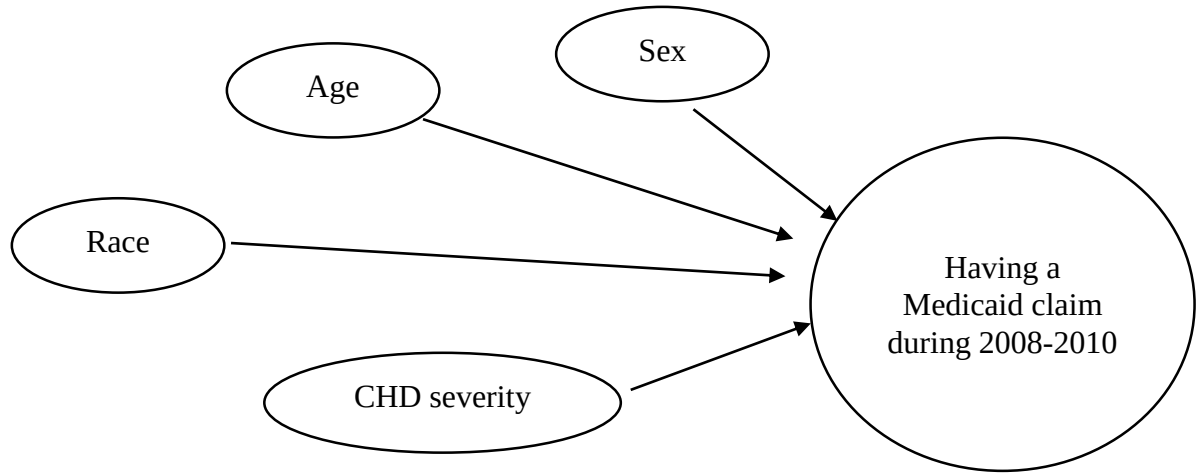
	Female 18-24			Male 18-24			Female 25-62			Male 25-62		
	OR	**95%CI**		**OR**	**95% CI**		**OR**	**95% CI**		**OR**	**95% CI**	
Outcome 1												
CHD Severity												
Severe	0.74	0.47	1.17	**1.68**	**1.06**	**2.67**	1.45	0.98	2.16	**1.89**	**1.24**	**2.88**
Shunts	1.11	0.78	1.59	**2.54**	**1.73**	**3.71**	1.08	0.81	1.45	**1.40**	**1.01**	**1.94**
Shunts & Valve	**1.85**	**1.25**	**2.73**	**4.20**	**2.82**	**6.25**	**1.33**	**1.01**	**1.76**	**1.73**	**1.26**	**2.36**
Valve	1.13	0.20	6.55	2.58	0.44	15.14	0.82	0.20	3.46	1.07	0.25	4.52
Other	0.96	0.62	1.49	**2.18**	**1.41**	**3.36**	1.26	0.91	1.74	**1.63**	**1.17**	**2.28**
Outcome 2												
CHD Severity												
Severe	**1.84**	**1.01**	**3.33**	1.14	0.605	2.137	**5.01**	**2.77**	**9.05**	**2.59**	**1.34**	**5.02**
Shunts	1.15	0.64	2.09	0.71	0.37	1.371	1.06	0.66	1.69	0.55	0.32	0.93
Shunts & Valve	1.95	0.91	4.19	1.21	0.543	2.675	**4.11**	**2.38**	**7.09**	**2.13**	**1.16**	**3.89**
Valve	0.35	0.03	4.62	0.22	0.016	3.015	0.39	0.06	2.67	0.20	0.03	1.42
Other	2.00	0.77	5.22	1.24	0.469	3.266	2.11	1.09	4.10	1.09	0.55	2.15

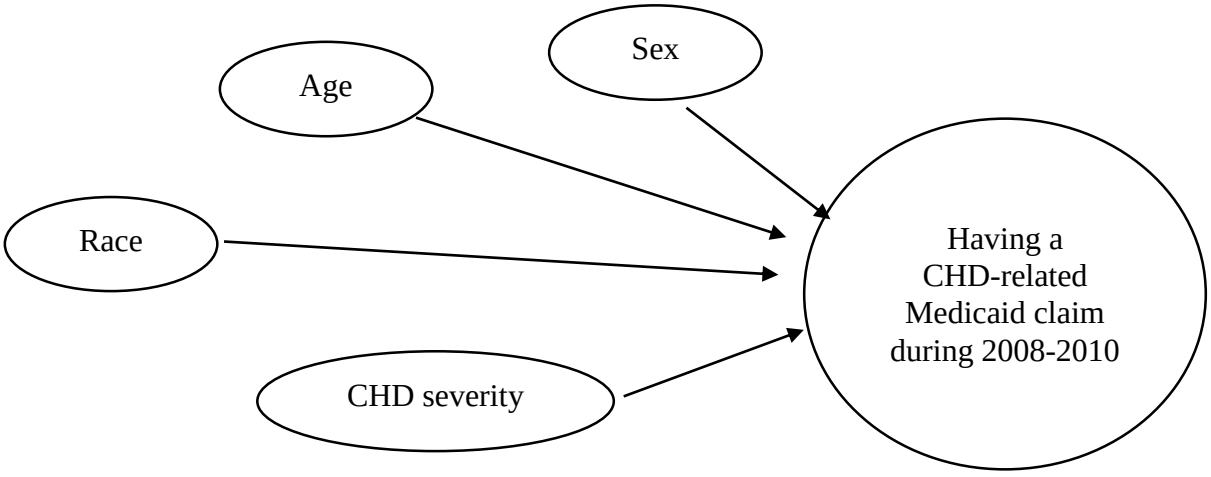
* *Outcome 1- a Medicaid Claim during 2008-2010 surveillance period;*
** *Outcome 2- a CHD-related Medicaid Claim during 2008-2010 surveillance period.*
Reference is Age < 18 years.

Note: Significant Odds Ratios are bolded.

FIGURES

Figure 1. DAG





CHAPTER IV: EXTENDED ANALYSIS

Sensitivity Analyses

Sensitivity analyses were performed to ensure that there were no differences in the characteristics of those that moved in Georgia into the catchment area during 2008-2010 compared to those that lived in the five counties from 1999 through 2010 and those who moved out between 2008 and 2010. These analyses were conducted to ensure that those who were excluded from this analysis who lived within the catchment area at any point during 1999-2010 did not move due to characteristics that were related to the outcome. Supplementary Tables 1 and 2 show that there are no significant differences between these groups. That is, there were no differences in CHD patients who lived in the catchment area between 1999 and 2007 in regards to sex and severity group for each category when compared to those who lived outside the catchment area between 1999 and 2007, but moved into the catchment area during 2008-2010 (Suppl. Table 1). Similarly, there were no differences between those that lived within the catchment area in 1999-2007, but moved in Georgia outside the catchment area in 2008-2010 and those who lived outside the catchment area between 1999 and 2007, but moved into the catchment area during 2008-2010 (Suppl. Table 2).

Final Adjusted Model Odds Ratio

Supplementary Table 3 summarizes the results of the final adjusted model for each outcome when considering age as the main effect and holding the other variables constant. Interactions between age as of 1/1/2008 and sex and age as of 1/1/2008 and CHD severity were found to be significant for both outcomes. The variables included in the final adjusted model for each outcome were age as of 1/1/2008, sex, CHD severity, plus the interaction terms between age as of 1/1/2008 and sex and age as of 1/1/2008 and

CHD severity. Generally, among males and females regardless of severity grouping and age (i.e., 18-24 and 25-62), the odds of not having a Medicaid claim during the 2008-2010 was greater when compared to the odds of not having a claim during this same period for those less than 18. For example, among females 18-24 years with a "Shunts + Valve" classification of CHD, the adjusted OR was 1.85 (95% CI: 1.25, 2.73) and among male counterparts of same age and CHD severity, the adjusted OR was 4.20 (95% CI: 2.82, 6.25). Among females 25-62 years with a "Shunts + Valves" classification of CHD, the adjusted OR was 1.33 (95% CI: 1.01, 1.76) and among males 25-62 years with a "Shunts + Valves" classification of CHD, the adjusted OR was 1.73 (95% CI: 1.26, 2.36). In regards to outcome 2, among females 18-24 years with a "Shunts + Valves" classification of CHD, the odds of having a Medicaid claim with no CHD-related diagnostic code during the surveillance period is 1.95 times that of the odds of having a claim with no CHD-related diagnostic code during this same period for those less than 18 years.

CHAPTER V: PUBLIC HEALTH IMPLICATIONS AND FUTURE DIRECTIONS

This study provides a detailed picture of adolescent and adult patients who had a CHD-related Medicaid claim between 1999 and 2007, who did and did not have at least one Medicaid-paid claim in Georgia between 2008 and 2010. Additionally, among those who had a Medicaid claim during 2008-2010, it provides a picture of which patients are more likely to have a CHD diagnosis on a Medicaid claim. Overall, it highlights which groups by age, sex, and CHD severity face the greatest barriers to accessing continuity of care, and among those who sought care, the issues associated with receiving appropriate specialized care.

Advances in pediatric medical care, including the improved diagnosis and treatment of children with congenital heart defects have significantly increased survivorship into adulthood. The increasing prevalence of CHD among adults necessitates improved transition from pediatric to adult cardiac care to ensure optimal quality of life. Literature states that the first gap in care is likely to occur around the age of 19-20 years where patients are changing or losing their health insurance coverage, and that the interval of the gap is greater than three years (62). Adams, et al. found that there was a steep decline in insurance rates after the age of 18 that continued through the mid-20s. From nationwide data from 2002-2003more than 10.7 million young adults aged 19 to 26 reported to be uninsured for all or part of the previous year (47).

Loss of insurance has serious implications on an individual's ability to access and utilize health care facilities. It is estimated that those patients who are uninsured (> 6 months) long-term are more likely to lack a usual source of care compared of those who uninsured for five months or less (30% vs. 17%) (48). Among the uninsured, those who

have the hardest time finding affordable coverage are those who stay uninsured the longest. These include those with low incomes, those in fair or poor health, and the middle-aged who are more likely to live with chronic health conditions (48). Public health insurance programs, such as Medicaid, were created to provide health care coverage to these groups, who otherwise may have no or inadequate medical insurance. These public programs have continued to improve access to care for many low incomes families. Medicaid, in many ways, has acted to bolster our nation's health care system by providing a safety net for many of the poorest, sickest, and most disabled individuals. However, it was found that the weak recovery rates in insurance coverage that occurs in the late 20s is directly related to the loss of public coverage. Additionally, the drop-off in public coverage across age groups, primarily affects lower income groups and those with special health care needs (47). This has serious implications for the care of CHD patients on Medicaid.

On January 1, 2014, the PPACA went into full effect which allowed for health insurance reforms and new health coverage options in Georgia and across the country. A main goal of the PPACA is to extend health coverage to nonelderly uninsured individuals across the country. Georgia, however, is among one of 23 states that are not currently implementing the Medicaid expansion, which could extend coverage to nearly 600,000 low-income uninsured adults in the state (28). Although, this study was conducted before this policy took effect, it highlights the need for the changes in Medicaid eligibility criteria that the PPACA now includes. This study supports literature which states that factors related to Medicaid eligibility (i.e., age and sex) are risk factors that increase the likelihood of not continuing care over time. Given these results, it is important that

Georgia reconsiders expanding Medicaid to provide coverage to the state's poorest and sickest, who essentially have aged out the system. Improving coverage will result in measurable improvements in health and productivity during this transitional period for America's young adults.

APPENDICES

Appendix A. Marelli's Congenital Heart Defect Severity Ratings

Severity	SevCode	ICD-9-	ICD-9-CM Description
Severe	1	745.0	Common Truncus
Severe	1	745.1	Transposition of the Great Arteries (TGA)
Severe	1	745.10	Complete TGA (dextro-TGA), NOS or classical
Severe	1	745.11	DORV, or incomplete TGA
Severe	1	745.12	Corrected TGA (levo-TGA)
Severe	1	745.19	TGA OS
Severe	1	745.2	Tetralogy of Fallot
Severe	1	745.3	Single Ventricle, or cor triloculare
Severe	1	745.6	Endocardial Cushion Defect (aka AVSD)
Severe	1	745.60	Endocardial Cushion Defect (aka AVSD) unspecified
Severe	1	745.61	ASD-1 (primum)
Severe	1	745.69	Endocardial Cushion Defect (aka AVSD) Other
Severe	1	746.01	Pulmonary valve atresia or absence
Severe	1	746.1	Tricuspid atresia, stenosis or absence
Severe	1	746.7	HLHS
Severe	1	747.11	Interrupted aortic arch
Severe	1	747.41	Total anomalous pulmonary venous return (TAPVR)
Shunts	2	745.4	VSD
Shunts	2	745.5	ASD2 or PFO
Shunts	2	745.8	Other specified defect of septal closure
Shunts	2	745.9	Unspecified defect of septal closure
Shunts	2	747.0	PDA
Shunts	2	747.1	Coarctation of aorta
Shunts+Valves	3		(depends on ICD codes of the combination)
Valve	4	746.0	Anomalies of pulmonary valve
Valve	4	746.00	Pulmonary valve anomaly, unspecified
Valve	4	746.02	Pulmonary valve stenosis
Valve	4	746.09	Pulmonary valve anomaly, other
Valve	4	746.2	Ebstein Anomaly
Valve	4	746.3	Aortic valve stenosis
Valve	4	746.4	Aortic insufficiency or bicuspid/unicuspid aortic valve
Valve	4	746.5	Mitral stenosis or mitral valve abnormalities
Valve	4	746.6	Mitral insufficiency
Valve	4	747.3	Anomalies of Pulmonary artery
Valve	4	747.31	Pulmonary artery atresia, coarctation, or hypoplasia
Valve	4	747.39	Anomalies of Pulmonary artery, other
Other	5	745.7	Cor biloculare
Other	5	746.8	Other Specified anomalies of heart
Other	5	746.81	Subaortic stenosis

Other	5	746.82	cor triatrium
Other	5	746.83	Infundibular or subvalvar pulmonary stenosis
Other	5	746.84	Obstructive anomalies of heart
Other	5	746.85	Coronary artery anomaly
Other	5	746.87	Malposition of heart or apex
Other	5	746.89	Other specified anomaly of heart (various types)
Other	5	746.9	Unspecified defect of heart
Other	5	747.2	Other anomaly of the aorta
Other	5	747.20	Anomalies of aorta, unspecified
Other	5	747.21	Anomaly of aortic arch
Other	5	747.22	Atresia or stenosis of aorta
Other	5	747.29	Other anomaly of aorta
Other	5	747.4	Anomalies of great veins
Other	5	747.40	Anomalies of great veins, unspecified
Other	5	747.42	Partial anomalous venous return (PAPVR)
Other	5	747.49	Other anomalies of great veins
Other	5	747.9	Unspecified anomalies of circulatory system

***Gray** = Only keep as separate defect if isolated CHD*