Distribution Agreement

In presenting this thesis or dissertation as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis or dissertation in whole or in part in all forms of media, now or hereafter known, including display on the world wide web. I understand that I may select some access restrictions as part of the online submission of this thesis or dissertation. I retain all ownership rights to the copyright of the thesis or dissertation. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation.

Signature:

_____ _____

Date

Preventive care and medical homes among children with heart conditions, National Survey of Children's Health , 2016-2017

By

Amber Broughton

Behavioral Sciences and Health Education

_____

Eric Nehl

Committee Chair

_____

Sherry Farr

Committee Member

_____

Tiffany Colarusso

Committee Member

Preventive care and medical homes among children with heart conditions, National Survey of Children's Health , 2016-2017

By

Amber Broughton, B.S.

Committee Chair: Dr. Eric Nehl, Committee Member: Dr. Sherry Farr, Dr.Tiffany Colarusso

An abstract of

Preventive care and medical homes among children with heart conditions, National Survey of Children's Health , 2016-2017

A thesis submitted to the Faculty of the

Rollins School of Public Health of Emory University

in partial fulfillment of the requirements for the degree of

Master of Public Health in

Behavioral Sciences and Health Education

2019

Abstract

Based on parent-reported data, an estimated 900,000 (1.3%) U.S. children currently have a congenital or acquired heart condition. Preventive care and medical homes play a critical role in the care of children with heart conditions. Thus, the purpose of this study was to estimate the prevalence of receipt of preventive care in the last 12 months and medical homes, and examine associated socioeconomic and demographic factors among U.S. children with heart conditions, both congenital and acquired. We analyzed population-based, parent-reported data from the 2016-2017 National Survey of Children's Health on 66,971 US children ages 0-17 years. We used chi square tests and the predicted marginals approach to multivariable logistic regression to generate adjusted prevalence ratios (aPRs) to assess whether having a heart condition was associated with receipt of preventive care and having a medical home. Among children with heart conditions, we also used the predicted marginal approach to multivariable logistic regression to examine characteristics associated with preventive care and medical homes. Among children with heart conditions (n=1,563), compared to those without (n=65,408), respectively, 91.0% and 82.6% received preventive care in the last 12 months [aPR=1.09 (1.05-1.14)] and 48.2% and 49.5% have a medical home [aPR=1.03 (0.92-1.15)]. After adjusting for other variables, children 0-5 years old (aPR: 1.09, 95% CI: (1.01-1.18)) and 6-11 years old (aPR: 1.08, 95% CI: (1.01-1.16)) were more likely than children 12-17 years to have received preventive care. Children with family incomes between 200%-399% FPL (aPR= 0.92, 95% CI:(0.85-0.98)) were less likely than children with family incomes ≥400% FPL to have received preventive care. Children with heart conditions categorized as "other" race [aPR=0.64, 95% CI: (0.42-0.97)], compared to non-Hispanic white children, and those with ≥ 2 other health conditions [aPR=0.58 , 95% CI: (0.43-0.77)], compared to none, were less likely to have a medical home. These results can guide ways to increase care of children with heart conditions within a medical home and

serve as a baseline to assess future changes in prevalence of preventive care and medical homes as recommendations within the AAP's policy statement are implemented.

Preventive care and medical homes among children with heart conditions, National Survey of Children's Health , 2016-2017

By

Amber Broughton, B.S.

Committee Chair: Dr. Eric Nehl, Committee Member: Dr. Sherry Farr, Dr.Tiffany Colarusso

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health in
Behavioral Sciences and Health Education
2019

Table of Contents

Chapter 1: Introduction

Problem Definition

Heart Conditions

There are approximately 1.3% of U.S. children, or an estimated 900,000 U.S. children who currently have a heart condition (Chen, Riehle-Colarusso, Yeung , Smith, & Farr, 2018). Children may be born with a heart condition, known as a congenital heart defect (CHD) or develop one over time, an acquired heart condition. For purposes of this thesis, the term "heart condition" refers to both CHD and acquired heart conditions. Both types of heart conditions are explained in more detail below.

Congenital Heart Defects

About 40,000 U.S. children per year are born with congenital heart defects (CHDs) (Centers for Disease Control and Prevention, 2018a; National Institute of Health, 2018), making CHDs the most common birth defects and a leading cause of birth defect-associated infant illness and death in the United States. CHDs are structural abnormalities of the heart and great vessels that occur during development in utero and are present at birth, 25% of which are considered critical, or needing intervention during the first year of life (Oster et al., 2013). It is estimated that 69% children with critical congenital heart defects (CCHD) will survival to 18 years of age which is significantly lower than that among children with non-critical CHD (95%); Yet , medical care and survival of children with CCHD continue to improve (Oster et al., 2013). While the cause of most CHDs is unknown, approximately 12% of children with CHDs have chromosomal abnormalities (Hartman RJ et al., 2011).

Individuals with CHDs experience higher rates of comorbidities and cognitive issues (Marino et al., 2012), as well as higher hospital costs than individuals without CHDs (Cora et al., 2013). Children with CHDs, compared to those without, experience other health complications such as asthma, ear infections, and neurodevelopmental issues (Razzaghi, Oster, & Reefhuis, 2015) and require more special education services (Riehle-Colarusso et al., 2015). In 2013, more than $6.1 billion in hospital cost went towards individuals with CHDs (Arth et al., 2017). Predictably, parents caring for children with CHDs report substantial levels of emotional stress and financial burdens (Connor, Kline, Mott, Harris, & Jenkins, 2010; McClung, Glidewell, & Farr, 2018).

Acquired heart conditions

In contrast to congenital heart defects (CHDs), some children develop heart conditions after birth, such as Kawasaki disease and rheumatic heart disease. However, the prevalence of all types of acquired heart conditions is unknown. No studies have been published on prevalence, comorbidities and hospital costs for children with acquired heart conditions as a whole. However, some U.S. studies have examined individual acquired heart conditions such as Kawasaki disease and rheumatic heart disease (Beaudoin et al., 2015; Belay, Holman, Maddox, Foster, & Schonberger, 2003; Kuo, Chang, Wang, Li, & Chang, 2016; Wang & Kuo, 2017). Approximately 7,000 children are diagnosed annually with Kawasaki disease (Seattle Children's Hospital, 2018), and rheumatic heart disease affects 3.2 per 1,000 children (Beaudoin et al., 2015)

Preventive care

A preventive care visit, also known as a well-child visit, is used to assess a "child's physical, behavioral, developmental, and emotional status" (American Academy of Pediatrics,

2002). Preventive care visits may play an important role in screening and identifying issues of concern among children with heart conditions and may lead to fewer unplanned hospitalizations among children with medical complexities, such as heart conditions (Shumskiy et al., 2018). The American Academy of Pediatrics (AAP) recommends that children under 3 years of age receive preventive care visits at regularly scheduled intervals throughout the year and children between 3-21 years of age receive an annual preventive care visit (American Academy of Pediatrics, 2014). Based on parent report, 91 percent of U.S. children under 6 years of age (Child Trends Databank, 2014) and 82% of older children attended a preventive care visit in 2013 (National Survey of Children's Health, 2011-12). However, based on Medicaid claims data, only about a quarter of U.S. children with medical complexities received an annual preventive care visit over a 5-year period (Shumskiy et al., 2018). Based on national survey data, receipt of an annual preventive care visit was lowest among Hispanic, lower income, and uninsured children (Adams, Park, & Irwin, 2015). Only one study has examined preventive care among children with special healthcare needs (CSHCN) and heart conditions (Downing, Oster, & Farr, 2017). Using data from 2010, this study found that 90% of these children received preventive care in the last 12 months. Differences in these estimates may stem from the population under study (Medicaid-insured children and all CSHCN) and data source (Medicaid claims data and parent-report). No studies have examined preventive care among children with CHD or acquired heart conditions separately.

Medical homes

The medical home delivery model, delivered by a well-trained physician, contributes to providing comprehensive care and improved outcomes for patients (Homer et al., 2008; Strickland et al., 2009). A medical home may play an important role in the health of a child with

heart conditions, from the prenatal period through the end of adolescence (Lantin-Hermoso et al., 2017). According to the AAP, a medical home should provide seven care components, namely, care that is "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective" (American Academy of Pediatrics, 2018). Nationally, less than half of U.S. children have a medical home (Child and Adolescent Health Measurement Initiative, 2016), and this percentage is lower among children who are Hispanic and non-Hispanic black, who have lower family incomes, non-English speaking parents, and less educated parents (Stevens & Kim, 2016).

It is especially important for children with chronic or medically complex conditions such as heart conditions to have a medical home, not only to receive preventive care, but to manage their condition and coordinate their care. For these reasons, the AAP recently released a policy statement entitled "The Care of Children with Congenital Heart Disease in their Primary Medical Home", which provides the medical home guidelines for caring for a child with CHDs (Lantin-Hermoso et al., 2017). Yet, little information exists on what percent of children with CHD, or heart conditions in general, have a medical home. One study, published in 1994, found that, among a convenience sample of 92 children with CHD, all had a primary care provider (PCP)(Young, Shyr, & Schork, 1994). However, the PCP did not provide care for many of the child's healthcare needs and no information was provided on whether the child had a medical home. One study using data from the 2009-2010 National Survey of Children with Special Healthcare Needs (NS-CSHCN) reported that 37.1% of CSHCN and heart conditions had a medical home (Downing et al., 2017). However, the estimates were only among CSHCN, and exploring demographic and socioeconomic factors associated with having a medical home was not the authors' focus.

Justification and Goals of Research

The 2017 AAP policy statement, "The Care of Children with Congenital Heart Disease in their Primary Medical Home" (Lantin-Hermoso et al., 2017), emphasizes the importance of the PCP and medical home in the care of the child with CHD. However, only two studies, mentioned above, (Downing et al., 2017; Young et al., 1994) have examined the percent of children with CHD or any heart condition that have a medical home or received preventive care . Both studies are based on data collected in 2010 or earlier, one was a small convenience sample, and neither examined what characteristics are associated with the outcomes. Improved data on the care of U.S. children with heart conditions in a medical could help implementation and evaluation of care guidelines.

Thus, the purpose of this research is to estimate the prevalence of medical homes, receipt of preventive care, and associated socioeconomic and demographic factors among U.S. children with heart conditions, both congenital and acquired.

Theoretical framework

Social determinants of Health theory (SDOH) is a framework that has been defined as "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks"(U.S. Department of Health and Human Services, 2018) . Furthermore, social determinants of health are factors that are either social, economic, or political which impact an individual or populations health. Generally speaking, determinants of health consist of factors or constructs that may be biological, socioeconomic, psychosocial, behavioral, or social which can ultimately influence

health outcomes at the individual or population level either directly or indirectly (Centers for Disease Control and Prevention, 2018b)

SDOH can be categorized as a downstream or upstream of social determinants. A downstream social determinant is the most proximal cause of a health outcome, or the factor directly preceding the outcome. In contrast, an upstream social determinant influences a downstream social determinant and is defined as a fundamental cause that drives causal pathways to a particular health effect or outcome. Downstream social determinants can be considered micro-level such as changes in an individual's health-related behavior, beliefs or attitudes, and can often be prevented by an individual. Upstream social determinants are macro-level such as social, economic or policy changes that could ultimately affect the health of an individual, but which an individual may have less control over.

Overall, the constructs of the SDOH share a complex relationship that must be addressed on each level. The research questions in this study will focus on upstream determinants. **Figure 1** gives a conceptual depiction of both the upstream and downstream determinants (Braveman, Cubbin, Egerter, Williams, & Elsie, 2010). Medical care and personal behavior are downstream determinants of a person's health, while economic and social opportunities are upstream determinants.

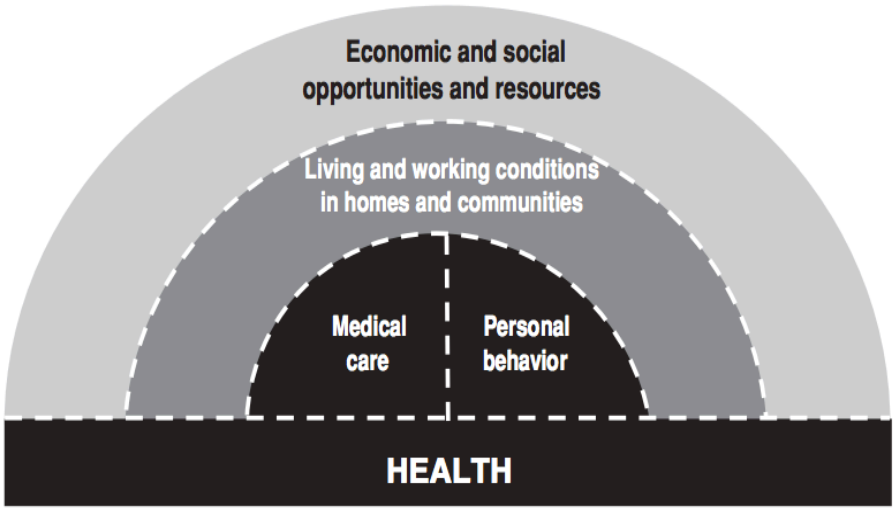


Figure 1 This figure is a conceptual representation of the upstream and downstream determinants

Another approach to SDOH is "place-based", meaning conditions occur in an environment or setting such as a specific geographical location, region, or neighborhood. Since this study encompasses all US children with heart conditions, this thesis will not be utilizing a SDOH place-based approach. However, it is important to denote that social and physical determinants can help explain how an individual is experiencing "place" and how "place" ultimately can impact a person's health (U.S. Department of Health and Human Services, 2018).

Overall, Healthy People 2020 approaches the social determinants of health using five key focus areas: 1) Neighborhood and Built Environment (e.g. environmental conditions and access to food supply), 2) Health and Health Care (e.g. access to health care and/primary care), 3) Social and Community Context (e.g. discrimination and social cohesion), 4) Education (e.g. enrollment in higher education and language and literacy) and 5) Economic Stability(e.g. poverty and employment) , which is depicted in **figure 2** (U.S. Department of Health and Human Services, 2018)**.** Only part of this theoretical framework, economic stability, education, and

health/healthcare, will be used to explain both research questions of interest. For the purposes of this study both health people 2020 approach and Braveman et.al ‘s approach to social determinants of health theory will be used as a theoretical framework to understand the demographic and socioeconomic factors that may impact children with heart conditions receiving preventive care and having a medical home.

Figure 2 Social Determinants of Health Model

While proximal factors are essential to understanding congenital and acquired heart conditions among US children, distal or upstream factors such as parental education and income, and insurance status are imperative to understand prevalence and demographic/socioeconomic factors that contributes to a child with heart conditions having a medical home in a greater context.

Health care access is a social determinant that is imperative to understanding the prevalence of children having medical homes and the socioeconomic factors that contribute to children having medical homes (Braveman, Egerter, & Williams, 2011; U.S. Department of Health and Human Services, 2018). Health care access can be indicated by social class gradients, which is associated with the level of social position (Hughes, Duderstadt, Soobader, & Newacheck, 2005; Newacheck, Hung, Jane Park, Brindis, & Irwin, 2003) . Low income families tend to not have continuity of care, fewer healthcare visits, and therefore have unmet healthcare needs. (Larson & Halfon, 2010). The Larson and Halfon study also found that health care access and utilization indicators such as ER use, no regular provider, etc, in the National Survey of Children's Health have been linked to reduction of access to health care services among children in lower income families (Larson & Halfon, 2010).

As aforementioned above, education is categorized as a social determinant of health (Braveman et al., 2011; U.S. Department of Health and Human Services, 2018). Several studies have linked higher rates of education to better overall health and health-related behaviors(Leganger & Kraft, 2003; Mirowsky & Ross, 1998). In contrast, those who have lower education status experience higher mortality rate and overall worse health outcomes(Bartley & Plewis, 2002). Additionally, preventive care is more likely to be sought by adults with higher educational attainment leading to better overall health outcomes than adults with lower educational attainment (Hummer & Lariscy, 2011).

Economic income stability is also categorized as a social determinant of health (Braveman et al., 2011; U.S. Department of Health and Human Services, 2018) . Several longitudinal studies show that economic resources such as income can essentially predict health outcomes with lower income or less economic resources being associated with poor health

outcomes (Avendano & Glymour, 2008; Daly, Duncan, McDonough, & Williams, 2002; Herd, Goesling, & House, 2007).

Study Objectives

The objectives of this study are to 1) estimate the prevalence of children with heart conditions who received preventive care in the last 12 months and have a medical home; 2) compare these estimates to estimates among children without heart conditions; and 3) examine the demographic and socioeconomic factors associated with receiving preventive care and having a medical home among children with heart conditions. Findings from this study can be used as a baseline estimate to assess changes over time that may occur after release of the AAP policy statement. The Social Determinants of Health theory (SDOH) will be utilized to understand both research questions of interest: (1) the estimated prevalence of children with heart conditions having a medical and seeking preventive care in the last 12 months and (2) understanding the demographic and socioeconomic factors that may contribute to a child with heart conditions having a medical home and receiving preventive care in the last 6 months. For the purposes of this research project, the Healthy People 2020 approach to SDOH will be used to describe research findings.

Research Questions

1. What is the prevalence of children with heart conditions that received preventive care in the last 12 months? How does this prevalence compare to children without heart conditions?
2. What is the prevalence of children with heart conditions that had a medical home? How does this prevalence compare to children without heart conditions?

3. Among children with heart conditions, what demographic and socioeconomic factors are associated with receiving preventive care and having a medical home and?

Chapter 2: Literature Review

Brief Introduction of the literature

Children can be affected by heart conditions, both congenital heart defects (CHDs) and acquired heart conditions. Approximately 1% of all children in the US are born with a CHDs, making CHDs the most common type of birth defect. There are many types of CHDs, ranging from minor defects that may need no intervention to critical CHDs, needing intervention during the first year of life (Gilboa et al., 2016; Oster et al., 2013). CHDs are routinely part of birth defects surveillance programs which monitor birth defects detected at birth or shortly thereafter. While researchers commonly group specific types of CHDs when analyzing data and presenting findings, little aggregate information is published on children with acquired heart disease. More commonly, researchers have examined specific types of acquired heart diseases, such as Kawasaki disease and rheumatic heart disease. The lack of information on acquired heart conditions among children may be due to several factors, e.g., heterogeneity of the conditions, insufficient surveillance of the conditions, and rarity of occurrence in children compared to adults. (USF Benioff Children's Hospital, 2019).

Preventive care and medical homes are important in caring for children with heart conditions, due to the complexity of their healthcare needs. The 2017 American Academy of Pediatrics (AAP) policy statement, The Care of Children with Congenital Heart Disease in their Primary Medical Home (Lantin-Hermoso et al., 2017), emphasizes the importance of the medical home in the care of the child with CHD. Understanding what percentage of U.S. children with heart conditions (both congenital and acquired) have medical homes and receive preventive care, and what characteristics are associated with these outcomes, can help policy makers and healthcare providers track implementation of guidelines over time.

The purpose of this review is to improve understanding of existing literature on prevalence of medical homes, receipt of preventive care, and associated socioeconomic and demographic factors among U.S. children with heart conditions, both congenital and acquired. However, due to the lack of literature regarding the prevalence of medical homes and preventive care among U.S. children with heart conditions, literature on U.S. children with other chronic conditions, medical complexity, and special healthcare needs is included, which may inform research on children with heart conditions. Initially, an overview was provided on CHDs and acquired heart conditions, including their prevalence at birth and during childhood, and associated educational and functional limitations. Next, we reviewed the existing peer-reviewed literature on the following topics specific to U.S. children with CHDs, heart conditions, and other chronic conditions or special health care needs: 1) prevalence of medical homes 2) receipt of preventive care; and 3) demographic and socioeconomic factors associated with having a medical home and receiving preventive care. Lastly, we discuss the Social Determinants of Health theoretical framework and the evidence within the literature which will be used to guide our research questions of interest.

Congenital Heart Defects

CHDs are structural abnormalities of the heart that occur during development in utero and are present at birth. About 40,000 U.S. children per year are born with CHDs (Centers for Disease Control and Prevention, 2018a; National Institute of Health, 2018), making CHDs one of the most common birth defects and a leading cause of birth defect-associated infant illness and death in the United States. Approximately, 25% of individuals born with CHDs have critical CHD (CCHDs) (Oster et al., 2013). The estimated survival to 18 years of age among children with CCHD (69%) is significantly lower than that among children with non-critical CHDs

(95%), yet medical care and survival of children with CCHDs continue to improve (Oster et al., 2013).

While the cause of most CHDs is unknown, approximately 12% of children with CHDs have chromosomal abnormalities (Hartman RJ et al., 2011). The most common genetic disorders associated with CHDs include Down syndrome and other aneuploidies, Williams syndrome, Noonan syndrome, CHARGE syndrome, VACTERL association, and deletion 22q11 syndrome (Ballweg, Wernovsky , & Gaynor, 2007; Pierpont et al., 2007).

Children living with CHDs commonly experience developmental disorders or disabilities (Marino et al., 2012; Razzaghi et al., 2015) and may need special education services (Riehle-Colarusso et al., 2015). Studies have shown that lower birth weight infants with complex CHDs have an increased risk of having developmental disabilities (Fuller et al., 2009; Gaynor et al., 2007; Tabbutt et al., 2008). Other studies have found that children with CHDs have an increased risk of neurodevelopmental outcomes such as autism spectrum disorders.(Antshel, Aneja, et al., 2007; Hultman, Spare´n, & Cnattingius, 2002; Wier, Yoshida, Odouli, Grether, & Croen, 2006).

Children with CHDs may also experience functional limitations in their daily lives. One study using 2009-2010 parent-reported data from the National Survey of Children with Special Health Care Needs found that children with special health care needs (CSHCN) and heart conditions experience functional limitations in the following areas: learning/concentration (35%), communication (21%), self-care (14%), gross motor skills (12%), and fine motor skills (10%) (Farr, Downing, Riehle-Colarusso, & Abarbanell, 2018). Similarly, other studies have found that children with CHD experience difficulty with self-care which results in a lower quality of life compared to children without CHDs (Mussatto & Tweddell, 2005; Walker, Gauvreau, & Jenkins, 2004). Children with complex CHDs have also experienced impaired

social cognition (Bru¨ne & Bru¨ne-Cohrs, 2006) making it difficult to understand self and other individual social actions or interactions (Antshel, Faraone, et al., 2007; Bellinger, 2008; Niklasson, Rasmussen, O´skarsdo´ttir , & Gillberg 2009; Sznajer et al., 2007). Moreover, young adults with CHDs are at risk for psychological distress as well increased difficulty with areas of vocation, social and domestic environments (Lyon, Kuehl, & McCarter, 2006).

Healthcare cost plays a tremendous role in caring for children with heart conditions. As CHD-related medical care and treatment has advanced over time, hospital cost has increased simultaneously. One study using the Healthcare Cost and Utilization Project 2013 inpatient sample found that CCHDs had the highest mean cost among other cardiovascular defects (Arth et al., 2017). Families of children with CHDs more often report financial burdens and emotional stress (Connor et al., 2010).

Acquired Heart Conditions

In contrast to CHDs, some children acquire or develop heart conditions after birth. Acquired heart conditions may include Kawasaki disease, rheumatic heart disease, arrhythmias, cardiomyopathy, and endocarditis. The prevalence of acquired heart conditions as a whole is unknown. However, 7,000 children are diagnosed annually with Kawasaki disease (Seattle Children's Hospital, 2018) and rheumatic heart disease affects 3.2 per 1,000 children (Beaudoin et al., 2015). Less literature exists on associations between acquired heart disease and developmental and educational issues in children. However, limited studies, focusing on Kawasaki disease, have found no statistically significant associations between Kawasaki disease and cognitive development (Kuo et al., 2016; Wang & Kuo, 2017).

Preventive Care

A preventive care visit, also known as a well-child visit, is used to assess a "child's physical, behavioral, developmental, and emotional status" (American Academy of Pediatrics, 2002). The AAP recommends that children under 3 years of age receive more frequent preventive care visits throughout the year and children between 3-21 years of age receive an annual preventive care visit (American Academy of Pediatrics, 2014). Based on parent report, 91 percent of U.S. children under 6 years of age (Child Trends Databank, 2014) and 82% of older children attended a preventive care visit in 2013 (National Survey of Children's Health, 2011-12). Several studies have shown that well-child visits for children in general, as well as those with medical complexity, may decrease pediatric hospitalizations (Shumskiy et al., 2018a; Tom, Mangione-Smith, Grossman, Solomon, & Tseng, 2013; Tom et al., 2010). Preventive care or well-child visits can also detect delays in development (Marino et al., 2012), and assess modifiable risk factors such as blood pressure and cholesterol levels, in order to reduce future health risk (American Academy of Pediatrics, 2014). For children with chronic conditions, preventive care may reduce the need for more intensive care for their condition (Morris, Schettine, Roohan, & Gesten, 2011). Thus, well-child visits are imperative to early detection and treatment of disease in a child (American Academy of Pediatrics, 2002).

Preventive care among US children with heart conditions

A systematic review of the literature was conducted to find all peer-reviewed published literature on preventive care visits and associated factors among children with heart conditions. We searched PubMed for all literature published through September 2018 to determine studies that examined any aspect of preventive care among US children with heart conditions. The literature search used the following search terms and MeSH headings: (preventive care,

preventive medicine, OR well-child visits) AND (congenital heart defects, congenital heart disease, OR heart conditions). The search was limited to studies of any design that conducted primary data collection and focused on children from ages 0-17 years of age. We also included relevant studies found when conducting the literature search on medical homes. Overall, our search yielded 40 articles, of which 1 was considered relevant to the topic and met our inclusion criteria. The other 39 articles were excluded because studies either did not focus on preventive care or did not provide information that discussed the relationship between preventive care among children with heart conditions.

This study is described in detail above in the section on medical homes. Downing and colleagues examined parent-reported preventive health care visits among children aged 12-17 years with special healthcare needs and heart conditions (Downing et al., 2017). The authors found that 90% of CSHCN attended a well-child visit in the last 12 months and the prevalence of attendance did not differ by heart condition status. The authors did not examine factors associated with attendance at a well-child visit.

Preventive care among US children living with other chronic diseases

Due to the lack of literature on preventive care and associated factors among U.S. children with heart conditions, we expanded the initial literature search to include studies examining preventive care and associated factors among U.S. children living with other chronic conditions, medical complexity, or special healthcare needs.

Findings from one study suggest that CSHCN attend well-child visits more frequently than children without special healthcare needs (Van Cleave & Davis, 2008). Other studies have examined preventive care among Medicaid-covered children with chronic illnesses or children

with medical complexities (Morris et al., 2011; Shumskiy et al., 2018b). Across NY State, 60 to 89% of Medicaid-covered children and adolescents had preventive care visits, depending on age and presence and severity of chronic disease (Morris et al., 2011). However, in another study, among 10 states, only 28% of Medicaid-covered children had preventive care visits for 4 or 5 out of 5 years examined (Shumskiy et al., 2018).

Among CSHCN and those with medical complexity, child's age (Morris et al., 2011; Van Cleave & Davis, 2008; Van Cleave et al.) and chronic condition status (e.g. minor or significant), were associated with receiving preventive care or attending well-child visits(Morris et al., 2011; Shumskiy et al., 2018; Van Cleave & Davis, 2008; Van Cleave et al.). In one study, authors found that, among children with significant and minor chronic conditions, respectively, approximately 85% and 82% of 15-month-olds, 85% and 89% of children 3-6 years of age, and 70% and 68% of adolescents had well-child visits. These estimates were slightly higher than those for healthy children (15 month-olds: 79%; 3-6 year-olds: 82%; and adolescents: 60%)(Morris et al., 2011). One other study found similar results, with older children with medical complexity attending well-child visits less frequently than younger children with medical complexity (Shumskiy et al., 2018). These authors also found that CSHCN ages 6-12 years were twice as likely to have had a well-child visit in the past year as children without special health care needs (Shumskiy et al., 2018)

Medical Homes

The American Academy of Pediatrics (AAP) defines the characteristics of a medical home in seven components: "accessible, continuous, comprehensive, family-centered,

coordinated, compassionate and culturally effective"(American Academy of Pediatrics, 2018). The seven characteristics of a medical home in more detail are as follows:

- A medical home is accessible when it consists of care being provided within a child's community, all insurance is accepted, and the physician is available when needed.
- A medical home is continuous when it consists of care being provided through each transition of the patients care whether its childhood to adulthood or a transfer of care between two facilities.
- A medical home is comprehensive when it consists of delivery of care by a well-trained physician who has developed a relationship with his/her patient and patient's family.
- A medical home is family-centered when the physician has a well-established relationship with the child and the his/her family.
- A medical home is coordinated when there is a plan of care that is developed by the primary care physician, child, and family and shared amongst other providers or parties involved in the patient's care.
- A medical home is compassionate when care providers exert effort in the well-being of a child and family.
- A medical home is culturally effective when it incorporates a child's and family's cultural background (beliefs, values, etc.) into a care plan.

Based on data from the 2016 National Survey of Children's Health, less than half of U.S. CSHCN have a medical home (Child and Adolescent Health Measurement Initiative, 2016). One study, using the National Survey of Children's Health from 2003-2012, examined national trends

from 2003-2012 in components of a child's medical home, found that comprehensive and family-centered care declined while access and continuity of care has improved (Stevens & Kim, 2016).

The medical home may reduce healthcare costs and improve coordination of care for patients with complex conditions (Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002; Mosquera et al., 2014). Additionally, patient-centered medical homes (PCMH) could potentially benefit children with complex CHDs by improving overall clinical outcomes, quality of life and reducing family stress (Fernandes & Sanders, 2015). Due to the complexity of needs among children with CHDs, the AAP provided specific recommendations within medical homes of children with CHDs, such as promoting care coordination and communication among the family, Primary Care Providers, and subspecialist; advocating for infrastructure support for caregivers; and facilitating patient access to pediatric subspecialty care (Lantin-Hermoso et al., 2017). Marino and colleagues also recommended surveillance, screening, and evaluation, when needed, for all children with CHDs and, for patients with CHDs classified as high risk of developmental disabilities, referral to formal developmental and medical evaluation (Marino et al., 2012).

Medical homes among U.S. children with heart conditions

We conducted a systematic review of the literature to find all peer-reviewed published literature on medical homes and associated factors among children with heart conditions. We searched PubMed for all literature published through September 2018 to determine studies that examined any aspect of medical homes among children with heart conditions. The literature search used the following search terms and MeSH headings: (medical home OR patient-centered care) AND (congenital heart defects, congenital heart disease, OR heart conditions). The search

was limited to studies of any design that conducted primary data collection and focused on children from ages 0-17 years of age. In order for the article to meet inclusion criteria, it was important for the studies to discuss children with CHDs and medical homes. Overall, our search yielded 16 articles, of which only 2 were considered relevant to the topic and met our inclusion criteria. The 14 excluded studies either did not focus on heart conditions or did not provide information that discussed the relationship between medical homes among children with heart conditions.

The first study used a convenience sample of 92 children with serious heart disease, defined as requiring 4 or more annual visits to a pediatric cardiology clinic (Young et al., 1994). The children's parents, primary care physicians (PCP) and pediatric cardiologists were surveyed to determine their beliefs about the roles of PCPs in the medical care of the children. Researchers used three questionnaires (for parents, PCPs and pediatric cardiologists) that consisted of 16 medical care needs specific to a child with serious heart disease (e.g. preventive care, cardiac care, and care of chronic illness). Results showed that all children within the study had a PCP, a component of the medical home care model. Over 80% of parents reported taking their child to a PCP for preventive care. However, 35% of parents reported that it is best to see a pediatric cardiologist for any of the child's health problems. Over 40% of parents reported that it would be helpful if the PCP discussed with him/her which doctor to call for which kind of problem. This is in contrast to over half of PCPs and pediatric cardiologists reporting that the PCP can provide nearly all medical care for children with serious heart disease. The authors suggest that PCPs describe to the parents their integral role in the care of a child with serious heart disease (Young et al., 1994).

The second study assessed the prevalence and predictors of healthcare transition-related discussions between providers and parents of CSHCN and heart problems, including CHDs (Downing et al., 2017). Researchers used parent reported data from the 2009-2010 National Survey of Children's Health on 12 -17-year-olds with special healthcare needs and heart conditions. While not a focus of the study, the authors reported that 37.1% of adolescents with heart problems had a medical home. The authors did not provide information on factors associated with having a medical home. (Downing et al., 2017).

Medical homes among U.S. children living with other chronic diseases

Due to the lack of literature on prevalence of medical homes and associated factors among U.S. children with heart conditions, we expanded the initial literature search to include studies examining prevalence of medical homes and associated factors among U.S. children with other chronic conditions, including those with special healthcare needs.

Studies found used parent-reported data as well as a combination of parent-report (53%) and medical record data (51.3%). Based on all data sources, about half (51.3%-53%) of US children with special health care needs did not have a medical home (Lin, Romley, & Carlin, 2018; Singh, Strickland, Ghandour, & van Dyck, 2009; Strickland et al., 2009). Based on data from the 2005-2006 NSCSHCN, the prevalence of children with special health care needs that lack medical homes vary throughout the US with the lowest rates in Ohio (46%) and Iowa (46%) and higher rates in Alaska (59%) and New Jersey (61%) (Singh et al., 2009). Overall, rates of having medical homes are higher in Midwestern states and lower in coastal states (Singh et al., 2009). Rates of having medical homes are also higher in metropolitan areas (Lin et al., 2018).

Individual factors associated with whether CSHCN or chronic conditions have medical homes included child's age and sex, family income, insurance status, race/ethnicity, and parent's education level (Lin et al., 2018; Mulvihill et al., 2007; Singh et al., 2009; Strickland et al., 2009). Children 0-5 years of age, were more likely to have a medical home compared to 6-11 year-olds and 12-17 year-olds (Singh et al., 2009) . In one study, male children were more likely to have a medical home than female children (Lin et al., 2018). Families of CSHN whose income is less than 100% of the federal poverty level (FPL) were half as likely to have a medical home than those whose family income was ≥400 of the FPL (Singh et al., 2009; Strickland et al., 2009). Similarly, another study found that as poverty increased, the proportion of CSHN having a medical home decreased (Mulvihill et al., 2007). Whether the child had insurance coverage was associated with having a medical home in some (Singh et al., 2009; Strickland et al., 2009), but not all studies (Mulvihill et al., 2007).

Other predictors that significantly affected access to medical homes among CSHCN included race/ethnicity (Singh et al., 2009; Strickland et al., 2009), severity of child's condition (Singh et al., 2009; Strickland et al., 2009), and parent's education level (Mulvihill et al., 2007; Singh et al., 2009). Non-Hispanic white children, compared to Hispanic, non-Hispanic black and other non-white CSHCN, were 50% to 200% more likely to have a medical home (Singh et al., 2009). One study was consistent with these findings, with 52.78% of non-Hispanic white CSHN having access to medical homes followed by other non-white (43.36%), non- Hispanic black (36.56%) and Hispanic CSHCN (32.24%)(Strickland et al., 2009). Children with conditions that limited their activity were also less likely to have a medical home (Singh et al., 2009; Strickland et al., 2009). Furthermore, one study found that CSHN and non-CSHN in Alabama whose

parents have less than a high school education were less likely to have a medical home (Singh et al., 2009).

Overall, we found only two studies that examined having a medical home and receipt of preventive care among children with heart conditions (Downing et al., 2017; Young et al., 1994). However, more studies have examined these issues among CSHCN and those with other chronic conditions and medical complexities. Understanding what percentage of U.S. children with heart conditions have medical homes and receive preventive care, and what characteristics may be associated with these outcomes, can help policy makers and healthcare providers track implementation of guidelines over time. Thus, the goals of this research are to improve understanding of the prevalence of medical homes, receipt of preventive care, and associated socioeconomic and demographic factors among U.S. children with heart conditions, both congenital and acquired.

Social Determinants of Health Theory

The Social Determinants of the Health (SDOH) are "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks"(U.S. Department of Health and Human Services, 2018). The SDOH theory framework was not used to explain the prevalence of children with heart conditions that have medical homes and the socioeconomic factors that contribute to children with heart conditions having a medical home in previous literature. Thus, this will be the first study to do so. Furthermore, very few studies in our literature review mentioned the SDOH framework as a part of their analysis. While this was a limitation for our literature review, we were able to identify studies that used constructs of the SDOH to explain

their research findings. Because this literature review will be used to inform the upstream factors such as parental education and income, and insurance status to understand the prevalence and demographic/socioeconomic factors that contributes to a child with heart conditions having a medical home in a greater context, we sought to examine constructs of the SDOH such health care access, education and economic stability in studies that discussed medical homes, preventive care or overall general health.

Health Care Access

Health care access is one of the most integral constructs of SDOH theory in this study being that our primary focus is understanding the prevalence of children having medical homes and the socioeconomic factors that contribute to children having medical homes (Braveman et al., 2011; U.S. Department of Health and Human Services, 2018). Social class gradients can determine an individual's health care access (Hughes et al., 2005; Newacheck et al., 2003) . In fact, among low income families there are unmet healthcare needs, fewer health care visits, and health services tend to lack continuity (Larson & Halfon, 2010). One study also found that health care access and utilization indicators in the National Survey of Children's Health have been linked to reduction of access to health care services among children in lower income families (Larson & Halfon, 2010).Insurance status also plays an integral role in health care status. Studies found children with special health care needs or chronic conditions were more likely to have a medical home if they had insurance coverage compares to those who did not have insurance coverage (Singh et al., 2009; Strickland et al., 2009).

Education

Education is a construct that is categorized as a social determinant of health (Braveman et al., 2011; U.S. Department of Health and Human Services, 2018). Studies within the literature denoted the general idea of higher educational attainment being associated with better overall better health (Bartley & Plewis, 2002; Hummer & Lariscy, 2011; Leganger & Kraft, 2003; Mulvihill et al., 2007; Singh et al., 2009). Two studies discussed the relationship of parental education and children with chronic conditions who have a medical home (Mulvihill et al., 2007; Singh et al., 2009). In fact, children with chronic conditions whose parents had less education were less likely to have access to a medical home (Mulvihill et al., 2007; Singh et al., 2009). Furthermore, one study found that higher mortality rates and overall worse outcomes were associated with lower education status (Bartley & Plewis, 2002).In contrast, other studies better overall health and health-related behaviors were associated with higher education levels (Leganger & Kraft, 2003; Mirowsky & Ross, 1998). Additionally, preventive care is more likely to be sought by adults with higher educational attainment leading to better overall health outcomes than adults with lower educational attainment (Hummer & Lariscy, 2011).

Economic Stability

Economic stability such as income levels, is another construct with the Social Determinants of Health theory framework (Braveman et al., 2011; U.S. Department of Health and Human Services, 2018). Studies have found that children with special health care needs who have family income is less than 100% of Federal Poverty Level (FPL) were less likely to have a medical homes than those who family income is ≥400 of FPL(Singh et al., 2009; Strickland et al., 2009). As aforementioned, several longitudinal studies show that economic resources such as income can essentially predict health outcomes with lower income or less economic resources

being associated with poor health outcomes (Avendano & Glymour, 2008; Daly et al., 2002; Herd et al., 2007).

Chapter 3: Student Contribution

The intended journal for this manuscript is the Journal of the American Academy of Pediatrics also known as *Pediatrics*. Amber Broughton, Dr. Sherry Farr, Dr. Tiffany Colarusso and Dr. Eric Nehl contributed to the conceptualization of the project. Dr. Sherry Farr conceptualized the study question, data source [National Survey of Children's Health (NSCH)], and epidemiological portion of the study, Dr. Tiffany Colarusso contributed subject matter expertise on congenital heart defects, and Amber Broughton and Dr. Eric Nehl conceptualized the theory portion of the paper. Before beginning the study, Amber Broughton conducted a detailed literature review on the topic, reviewed by Drs. Farr, Nehl, and Colarusso, and determined how this analysis would fill the gaps in the literature. Amber Broughton and Dr. Farr planned the analyses, data elements needed, and presentation of the results. Amber Broughton downloaded the publicly available NSCH data from the U.S. Census Bureau website, along with relevant data documentation. Amber first read documentation on how the NSCH data was collected and how NSCH-derived variables were created. Amber analyzed the data using SAS and SUDAAN, under the supervision of Dr. Farr.

All analytic results and their implications were critically reviewed by Amber Broughton, and Drs. Farr, Colarusso, and Nehl. All sections of the manuscript were drafted by Amber Broughton and reviewed and revised by Drs. Farr, Nehl and Colarusso.

Chapter 4: Manuscript

Introduction

Pediatric preventive care visits are opportunities for primary care providers (PCPs) to promote positive behaviors and identify issues of concern for children such as inadequate growth, neurodevelopmental and behavioral concerns, and obesity. These visits are especially important for children with medical complexities, such as certain heart conditions, who may be at higher risk for adverse outcomes (Shumskiy et al., 2018). Similarly, a medical home plays an important role in the health of a child with heart disease, from birth through the end of adolescence (Lantin-Hermoso et al., 2017). The medical home delivery model is delivered by a well-trained physician and contributes to providing comprehensive care and improved outcomes for patients (Homer et al., 2008; Strickland et al., 2009). According to the American Academy of Pediatrics (AAP), a medical home should provide care that is "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective", (American Academy of Pediatrics, 2018).

The 2017 AAP policy statement, The Care of Children with Congenital Heart Disease in their Primary Medical Home (Lantin-Hermoso et al., 2017), emphasizes the importance of PCPs and medical homes in the care of a child with congenital heart disease (CHDs). CHDs are a type of heart condition which is present at birth, affecting the structure and function of the heart.However, there are no estimates of the percent of children with CHDs, or heart conditions in general, who have medical homes. Only two studies,(Downing et al., 2017; Young et al., 1994) provided estimates for the percent of children with heart conditions, among children who have special healthcare needs, who have received preventive care in the last 12 months or that have a PCP, one component of the medical home. Both studies are based on data collected in

2010 or earlier, and neither examined the demographic characteristics associated with the outcomes among all children with heart conditions..

Understanding the percentage and characteristics of U.S. children with heart conditions receiving preventive care and having medical homes can inform strategies to improve these outcomes and track implementation of the AAP guidelines over time. Thus, the objectives of this study are to estimate the prevalence of the receipt of preventive care, having a medical home, and associated socioeconomic and demographic factors among U.S. children with heart conditions, both congenital and acquired.

Methods

This analysis used the 2016-2017 National Survey of Children's Health (NSCH) conducted by the U.S. Census Bureau and sponsored and directed by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), and Maternal and Child Health Bureau. The NSCH is a parent-reported, population-based, cross-sectional survey of U.S children ages 0-17 years, in all 50 states and the District of Columbia. The survey uses a complex sampling strategy to collect information, via mail or online, about children's health and well-being.

Parent-reported heart condition was the exposure for this analysis. Parents were asked "Has a doctor or other health care provider ever told you that this child has a heart condition? (yes/no)". If parents answered "yes", children were considered to have a heart condition.

The two outcomes for this analysis were receipt of preventive care in the past 12 months and having a medical home. The preventive care outcome is based on two questions. The first question asked "During the past 12 months, did this child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations or other

kind of medical care?". If parents answered "yes", then the parent was asked "During the past 12 months, how many times did this child visit a doctor, nurse, or other health care professional to receive a preventive check-up?" If parents answered "1" or "2 or more" to the second question, then the child was considered as having received preventive care in the last 12 months.

The second outcome, having a medical home, is an NSCH-derived variable that uses questions assessing each medical home component, with the constellation of questions deemed sufficient to generate national estimates of the percentage of U.S. children with medical homes (Bethell, Read, & Brockwood, 2004). To be considered as having a medical home, parents must report that their child has a personal doctor or nurse, a usual source for care, and family-centered care. For children who need referrals and/or care coordination, parents must also report that the child received needed referrals and coordinated care.

To assess whether a child had a personal doctor or nurse, parents were asked " Do you have one or more persons you think of as this child's personal doctor or nurse?" followed by two questions about usual sources for sick care: "Is there a place that this child USUALLY goes when he or she is sick or you or another caregiver needs advice about his or her health?" and "Where does this child USUALLY go?". Family-centered care is assessed by five questionsconsidering whether a physician spends enough time with the child, listens to parents carefully, is sensitive to family values/customs, gives needed information, and makes the family feel like a partner in care. Participants must answer 'usually or always' to each question in order to be considered as having family-centered care.

The fourth component of a medical home, receiving needed referrals, is composed of two questions. The parents are asked: "During the past 12 months, did this child need a referral to see any doctors or receive any services?" If the parent answered "yes", he/she is then asked: "How

much of a problem was it to get referrals?" The last component of a medical home, care coordination, is composed of 6 questions that assess communication between doctors when needed, communication between doctors and schools when needed, and getting needed help coordinating care. Participants are initially asked "Does anyone help you arrange or coordinate this child's care among the different doctors or services that this child uses?", if the parent answers "Did not see more than one health care provider in the past 12 months" then the child is not considered needing care coordination. Children who need referrals or care coordination must also meet the first three criteria (personal doctor or nurse, usual source for care, and family-centered care) in order to qualify as having a medical home.

Previous literature and the social determinants of health theory were used to determine the demographic and socioeconomic factors that may be associated with receipt of preventive care and having a medical home among children with heart conditions. Factors examined were child's sex, age, health insurance type, race/ethnicity, family income as a percent of the federal poverty level (FPL), and number of other health conditions, as well as parent's marital status and educational level.

We determined the percentage of children with missing data on heart condition, outcomes of interest, and relevant demographic/socioeconomic variables and used chi-square tests to compare children with and without missing data. Among children with data on all variables of interest, we generated weighted percentages and 95% confidence intervals to examine demographic and socioeconomic variables stratified by heart condition status. Next, we estimated the percentage of children with and without heart conditions that received preventive care, had a medical home, and reported the five individual components of the medical home. Among children with and without heart conditions, we used the predicted marginal approach to

logistic regression in separate multivariable models, one for each outcome, to examine whether having a heart condition is independently associated with receiving preventive care in the last 12 months and having a medical home. Additionally, among children with heart conditions, we used the same approach in two separate models to examine the associations between demographic and socioeconomic factors and each of the two outcomes: receiving preventive care in the last 12 months and having a medical home. To assess whether associations were generalizable to children with heart conditions without syndromes, we conducted all analyses again after excluding children with Down syndrome and other genetic conditions. All analyses were conducted in SUDAAN to account for the complex sampling design and weights were used to generate population-based estimates.

Results

There were 71,811 children whose parent or guardian completed the 2016-2017 NSCH. Of those, 6.7% (4,840) were excluded from our analysis due to missing data on one or more variables of interest. Therefore, 66,971 children were included in the analytic sample. The prevalence of having a heart condition did not differ among children included and excluded from the analysis ($p>0.05$). Children excluded from our sample, compared to those included, respectively, were less likely to have received preventive care in the last 12 months (79.6% vs 85.4%) and to have a medical home (46.7% vs 55.9%; $p<0.05$ for both). Larger percentages of children excluded from the analytic sample, compared to those included, respectively, had public, unspecified & no insurance (40.3% vs 26.1%) were Hispanic (15.2% vs 10.8%) or non-Hispanic black (10.0% vs 5.6%), had parents who were not currently married or cohabitating (25.4% vs 16.3%), were lower income (<=199% FPL: 43.7% vs 25.0%), and had parents with less education (≤ high school: 27.4% vs13.8%; $p<0.05$ for all, **Appendix A)**.

The majority of children with (n=1563) and without heart conditions (n= 65408), respectively, were male (51.6% and 50.9%), privately insured (53.0% and 58.5%), non-Hispanic white (58.8% and 52.6%), had married parents (70.9% and 80.1%), and had no other health conditions (55.7% and 76.0%) (Table 1). Heart condition status was significantly associated with marital status and number of health conditions ($p<0.05$ for both). Among children with heart conditions, 70.1% had parents who were married or cohabitating compared to 80.1% of children without heart conditions. Similarly, among children with heart conditions, 29.2% had 2 or more other health conditions compared to 11.5% of children without heart conditions. Children with heart conditions (47.0%), compared to those without (41.5%), more commonly had public, unspecified & no insurance, but this difference did not reach statistical significance ($p=0.08$). Children with heart conditions, compared to those without, respectively, were slightly more likely to be Non-Hispanic White (58.8% and 52.6%) and less likely to be Hispanic (19.1% and 24.1%) and other races (8.3% and 10.7%) although for several categories the 95% CIs overlapped.

A large majority of children both with and without heart conditions received preventive care in the last 12 months (91.0% and 82.6%, $p<0.001$; Table 2). After adjusting for demographic and health characteristics, children with heart conditions were slightly more likely to have received preventive care in the last 12 months [aPR=1.09 (1.05-1.14)]. However, less than half of children both with and without heart conditions met the criteria for having a medical home (48.2% and 49.5%, $p=0.67$). After adjusting for demographic characteristics, having a heart condition was not associated with having a medical home [aPR=1.03 (0.92-1.15)].

The prevalence of meeting individual medical home components ranged from 63.8% for care coordination to 87.8% for family centered care (Figure 1**)**. Children with heart conditions,

compared to those without, respectively, were less likely to have received all needed components of care coordination (63.8% vs 73.0%; $p<0.05$ for both). The prevalence of other medical home components did not differ among children with and without heart conditions.

Among children with heart conditions, those with the lowest prevalence of receiving preventive care in the last 12 months were 12-17 years of age (86.4%), publicly-insured or uninsured (89.7%), Hispanic (87.8%), with family incomes 200%-399% FPL (86.2%), and whose parents were never married (88.0%) (Table 3). After adjusting for other variables, children 0-5 years old (aPR: 1.09, 95% CI: (1.01-1.18)) and 6-11 years old (aPR: 1.08, 95% CI: (1.01-1.16)) were more likely than children 12-17 years to have received preventive care. Children with family incomes between 200%-399% FPL (aPR= 0.92, 95% CI:(0.85-0.98)) were less likely than children with family incomes ≥400% FPL to have received preventive care. Among children with heart conditions, receipt of preventive care was not associated with other demographic and health characteristics.

Among children with heart conditions, subgroups with the lowest prevalence of having a medical home were those who were publicly-insured or uninsured (41.1%), categorized as 'other races' (36.5%), who had a family income ≤199% FPL (43.1%), whose parents had a high school education or less (40.0%), and who had ≥ 2 other health conditions (33.5%) (Table 3). Among children with heart conditions, after adjusting for all variables, children categorized as "other" race (aPR=0.64, 95% CI: (0.42-0.97)), compared to non-Hispanic white children, those with ≥ 2 other health conditions (aPR=0.58 , 95% CI: (0.43-0.77)), compared to none, were less likely to have a medical home. Children 0-5 years of age (aPR=0.79 , 95% CI: (0.62-1.01)), compared to children 12-17 years of age and Hispanic children (aPR=0.69 , 95% CI:(0.47-1.01)), compared to non-Hispanic white children were also slightly less likely to have medical homes, although the

upper 95% CIs were above 1.0. Among children with heart conditions, no other variables were associated with having a medical home.

Discussion

To our knowledge, this is the first study to examine the prevalence of receiving preventive care, having a medical home, and associated demographic and socioeconomic characteristics among children with heart conditions. We found a large majority of all children, slightly more children with heart conditions than without, received preventive care in the last 12 months. However, less than half of children both with and without heart conditions met the criteria for having a medical home. Among children with heart conditions, receipt of preventive care was more common among younger children and less common among those with a family income between 200%-399% FPL; having a medical home was less likely among children with heart conditions categorized as "other" race and with ≥ 2 other health conditions.

The American Academy of Pediatrics (AAP) generally recommends that children under 3 years of age should receive more frequent preventive care visits throughout the year and children between 3-21 years of age should receive an annual preventive care visit (American Academy of Pediatrics, 2014). Our findings reveal that the large majority of U.S. children with heart conditions may be following those guidelines.

The AAP policy statement on the care of children with CHDs recognizes that patients with CHDs may have many healthcare needs for which their primary care provider (PCP)/medical home can provide or coordinate care (Lantin-Hermoso et al., 2017). Early in life, the PCP/medical home can ensure proper nutrition and growth, immunization needs are met, and assess neurodevelopmental concerns, and during childhood can provide guidance on exercise and sports participation, obesity prevention, and assist with the transition to adult care. These

functions are applicable to all children, but even more important for children with certain heart conditions such as CHDs. The PCP/medical home can also identify issues affecting families such as mental health issues and cardiopulmonary resuscitation training. Our results show that children with heart conditions, which includes CHDs, come in contact with their PCP at least annually, providing opportunities for the PCP to offer this type of care. However, our results also show that improvements could be made in ensuring children with heart conditions receive coordinated care in a medical home.

Demographic and socioeconomic characteristics associated with receiving preventive care and having a medical home among children with heart conditions, can be explained in context of the SDOH theoretical framework. Economic stability, particularly income level, can be a barrier to receiving preventive care and affect an individual's health care access. Low income families may have unmet healthcare needs, fewer health care visits, and health services tend to lack continuity (Larson & Halfon, 2010). Among children with heart conditions, prevalence of having a medical home was lowest among children who were publicly-insured or uninsured (41.1%), categorized as 'other races' (36.5%), had a family income ≤199% FPL (43.1%), whose parents had a high school education or less (40.0%), and who had ≥ 2 other health conditions (33.5%). Education attainment has been previously linked to overall better health (Bartley & Plewis, 2002; Hummer & Lariscy, 2011; Leganger & Kraft, 2003; Mulvihill et al., 2007; Singh et al., 2009). Similar to our results, children with chronic conditions whose parents had less education were less likely to have a medical home (Mulvihill et al., 2007; Singh et al., 2009). Among children with heart conditions, children categorized as 'other race' had the lowest prevalence of having a medical home, followed by Hispanic and non-Hispanic Black children. These disparities demonstrate the need to examine why children of lower

socioeconomic status and of minority racial-ethnic groups do not receive care in medical homes at the same rate as their counterparts. Understanding the drivers of health equity can inform tailored intervention strategies to decrease disparities and increase the prevalence of medical homes among children with heart conditions.

Only one study examined preventive care among children with heart conditions or CHDs (Downing et al., 2017).Others examined preventive care among children with special healthcare needs or medical complexities which may include children with heart conditions (Morris et al., 2011; Shumskiy et al., 2018; Van Cleave & Davis, 2008; Van Cleave et al.). Our results are similar to a study using national data from 2009-2010, which reported that 90% of children with heart conditions and special healthcare needs received preventive care in the last 12 months (Downing et al., 2017). In contrast, another study examining Medicaid-covered children and adolescents with medical complexities in New York State, found that 60-89% received preventive care, depending on age and presence and severity of chronic disease (Morris et al., 2011).

We found only one study related to medical homes among children with heart conditions. That study, published in 1994 and conducted among a convenience sample of 92 children with CHDs, found that all had a PCP (Young et al., 1994). However, the PCP did not provide care for many of the child's healthcare needs and no information was provided on whether the child had a medical home. Our findings on children with heart conditions are consistent with findings from previous studies on children with special healthcare needs and medical complexities in general. In studies using parent-reported (Singh et al., 2009; Strickland et al., 2009) and medical record data (Lin et al., 2018), about half of children with special health care needs had a medical home, but prevalence varied by state (Singh et al., 2009). Overall, rates of having medical homes were

higher in Midwestern states and lower in coastal states (Singh et al., 2009). Rates of having medical homes are also higher in metropolitan areas (Lin et al., 2018).

While this study provides national estimates for receipt of preventive care and having a medical home among children with heart conditions, there are limitations to our findings. First, the NSCH is parent-reported data and is not validated through medical records. Secondly, there was no information on whether the "heart condition" was acquired or congenital; thus, we were unable to examine outcomes stratified by type of heart condition. Finally, over 6% of children in our study had missing data on variables of interest. These children were less likely to receive preventive care and have a medical home; thus, we may have slightly underestimated the prevalence of our outcomes.

Conclusion

While over 90% of children with heart conditions receive preventive care annually, less than half receive their care in a medical home, with children least likely to receive coordinated care. Disparities in receipt of preventive care and having a medical home among children with heart conditions were found for children of lower socioeconomic status, racial/ethnic minorities, and those with ≥ 2 other health conditions. These results can serve as a baseline to assess future changes in prevalence of medical homes as recommendations within the AAP's policy statement are implemented. These findings may also guide further understanding of ways to increase care within a medical home among children with heart conditions.

Table 1. Characteristics of children by presence of a heart condition, National Survey of Children's Health, 2016 & 2017

	Heart condition		**No Heart Condition**		**Chi square p-Value**
	Unweighted No.	Weighted % (95% CI)	Unweighted No.	Weighted % (95% CI)	
Total	1563	2.2%	65408	97.8%	
Sex					**0.81**
Female	718	48.4% (42.7-54.1)	31958	49.1% (48.2-50.0)	
Male	845	51.6% (45.9-57.3)	33450	50.9% (50.0-51.8)	
Age					**0.12**
0-5	434	27.5% (23.4-32.0)	18972	32.4% (31.5-33.3)	
6-11	463	37.7% (31.9-43.8)	19617	33.9% (33.0-34.8)	
12-17	666	34.8% (29.8-40.2)	26819	33.7% (32.9-34.5)	
Health Insurance Type					**0.08**
Public, Unspecified & No insurance	512	47.0% (41.2-52.8)	16939	41.5% (40.5-42.4)	
Only Private	1051	53.0 % (47.2-58.8)	48469	58.5% (57.6-59.5)	
Race/Ethnicity					**0.06**
Non-Hispanic White	1142	58.8% (52.9-64.5)	46151	52.6% (51.7-53.5)	
Non-Hispanic Black or African American	94	13.7% (10.3-18.1)	3658	12.6% (12.0-13.4)	
Hispanic	156	19.1% (14.2-25.2)	7100	24.1% (23.1.-25.1)	
Other races**	171	8.3% (6.0-11.5)	8499	10.7% (10.2-11.2)	

Parent marital status					**0.01**
Never married, Divorced, separated or widowed	286	29.1% (23.4-35.4)	10619	19.9% (19.2-20.7)	
Married & not married but living with partner	1277	70.9% (64.6-76.6)	54789	80.1% (79.3-80.8)	
% Federal poverty level					**0.10**
<199%	424	43.6% (37.8-49.7)	16364	41.0% (40.1-42.0)	
200%-399%	532	29.5% (25.3-34.2)	20206	27.7% (26.9-28.5)	
≥400%	607	26.9% (23.0-31.2)	28838	31.3% (30.6-32.1)	
Parent education					**0.68**
Less than high school and High School (including vocational, trade or business school)	232	29.9% (24.0-36.6)	9002	26.9% (26.0-27.9)	
Some college or associate degree	374	21.7 (18.1-25.8)	14780	22.5% (21.8-23.3)	
College degree or higher	957	48.4% (42.8-54.0)	41626	50.5% (49.6-51.5)	
Number of health other conditions*					**<.001**
None	830	55.7% (50.2-61.1)	48289	76.0% (75.2-76.8)	
1	250	15.1% (11.5-19.5)	8579	12.4% (11.8-13.0)	
≥2	483	29.2% (24.8-34.0)	8540	11.5% (11.0-12.1)	

*Excludes heart conditions but includes allergies, arthritis, asthma, blood disorder, brain injury, palsy, cystic fibrous, diabetes, Down syndrome, epilepsy or seizure disorder, genetic condition, severe headache, Tourette syndrome, anxiety, depression, behavior problems, developmental delay, intellectual disability, speech disorder, learning disability, other mental health conditions, autism, ADHD, substance abuse.

Table 2. Prevalence of receiving preventive care in the past 12 months and having a medical home, by presence of heart condition, National Survey of Children's Health, 2016 and 2017

	Heart Condition	No Heart Condition		
	(weighted %, 95% CI)	**(weighted %, 95% CI)**	**Chi-Sq p-value**	**aPR* (95% CI)**
Preventive care in past 12 months			**<.001**	
Yes	91.0% (87.8-93.5)	82.6% (81.9-83.4)		1.09 (1.05-1.14)
Medical home			0.67	
Yes	48.2 % (42.6-53.9)	49.5% (48.6-50.4)		1.03(0.92-1.15)

*adjusted for sex, age, insurance type, race and ethnicity, marital status, federal poverty level, education level, number of other health conditions.

Table 3. Characteristics associated with receiving preventive care in the past 12 months and having a medical home among children with heart conditions, National Survey of Children's Health, 2016

	Preventive care visit, last 12 months			**Medical Home**		
	weighted %, 95% CI)	aPR* (95% CI)	**Chi-Sq p-value**	**weighted %, 95% CI)**	aPR* (95% CI)	**Chi-Sq p-value**
Sex			**0.91**			**0.24**
Female	91.2% (85.8-94.7)	1.01 (0.96-1.07)		51.8% (42.4-61.1)	1.08 (0.88-1.32)	
Male	90.9% (86.4-94.0)	---		44.9% (38.8-51.2)	---	
Age			**0.14**			**0.61**
0-5	94.2% (89.6-96.9)	1.09 (1.01-1.18)		47.3% (39.3-55.4)	0.79 (0.62-1.01)	
6-11	93.0% (89.1-95.6)	1.08 (1.01-1.16)		45.4% (34.5-56.8)	0.85 (0.67-1.09)	
12-17	86.4% (78.3-91.8)	---		52.0% (43.4-60.5)	---	
Health Insurance Status			**0.39**			**0.02**
Public, Unspecified & No insurance	89.7% (82.8-94.0)	0.96 (0.90-1.03)		41.1% (31.1-51.9)	0.95 (0.73-1.23)	
Only Private	92.3% (89.5-94.4)	---		54.6% (48.9-60.1)	---	
Race/Ethnicity			**0.79**			**0.05**
Non-Hispanic White	91.3% (88.0-93.8)	---		54.8% (48.4-61.1)	---	
Non-Hispanic Black or African American	93.6% (85.7-97.3)	1.04 (0.97-1.12)		40.6% (27.2-55.6)	0.87 (0.61-1.25)	

Hispanic	87.8% (72.2-95.2)	1.00 (0.94-1.08)		38.7% (23.8-55.9)	0.69 (0.47-1.01)	
Other races**	92.3% (84.0-96.5)	1.02 (0.94-1.11)		36.5% (23.9-51.3)	0.64 (0.42-0.97)	
Parent marital status			**0.31**			**0.22**
Never married, Divorced, separated or widowed	88.0% (77.7-93.9)	0.95 (0.86-1.04)		41.7% (28.6-56.0)	0.94 (.71-1.26)	
Married & not married but living with partner	92.3% (89.5-94.3)	---		50.9% (45.2-56.7)	---	
% Federal poverty level			**0.11**			**0.03**
≤199%	92.1% (87.5-95.1)	0.98 (0.92-1.05)		43.1% (32.5-54.5)	0.95 (0.71-1.27)	
200%-399%	86.2% (77.6-91.9)	0.92 (0.85-0.98)		46.6% (39.0-54.4)	0.85 (0.68-1.06)	
≥400%	94.6% (90.4-97.1)	---		58.4% (50.9-65.5)	---	
Parent education			**0.99**			**0.19**
Less than high school and High School (including vocational, trade or business school)	91.0% (84.5-94.9)	1.01 (0.95-1.08)		40.0% (26.7-54.9)	0.88 (0.62-1.23)	
Some college or associate degree	91.4% (86.0-94.8)	1.01 (0.95-1.08)		47.7% (38.9-56.7)	0.96 (0.75-1.24)	
College degree or higher	90.9% (85.1-94.6)	---		53.6% (47.0-60.0)	---	

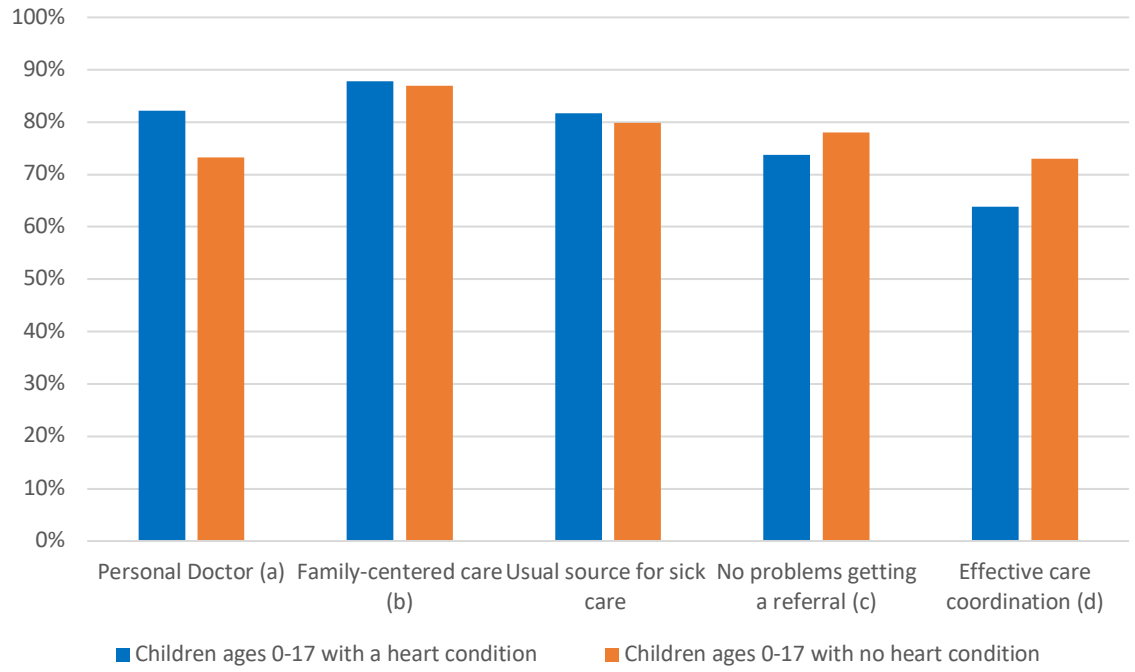
Number of other health conditions*		**0.54**		**<.001**
None	91.5% (87.4-94.4)	---	56.8% (48.7-64.5)	---
1	85.9% (70.56-93.9)	0.95 (0.86-1.05)	45.2% (32.5-58.6)	0.82 (0.62-1.09)
≥2	92.7% (87.5-95.9)	1.03 (0.97-1.09)	33.5% (26.0-42.1)	0.58 (0.43-0.77)

PR: prevalence ratio

CI: Confidence interval

*adjusted for sex, age, insurance type, race and ethnicity, marital status, federal poverty level, education level, other health conditions

Figure 1. Prevalence of medical home components by heart condition status, National Survey of Children's Health 2016-2017



[a] Among 66971 children
[b]Among 59,566 children who had a health care visit in the past 12 months
[c]Among 12,552 children who needed referrals during the past 12 months
[d]Among 37,601 children who needed coordinated care and have ≥2 services during past 12 months

Chapter 5: Public Health Implications

Public Health Implications

There are various implications for public health research and practice to improve access to preventive care and medical homes among children with heart conditions. Our study found that 9 out of 10 children with heart conditions had received preventive care in the last 12 months, but less than half had a medical home. While the prevalence for children with heart conditions that had received preventive care aligned with the American Academy of Pediatrics (AAP) recommendations, the prevalence of medical homes suggest areas of improvement for pediatric care. Additionally, few demographic and socioeconomic factors were significantly associated with receipt of preventive care and having a medical home among children with heart conditions. However, children with the lowest prevalence estimates of receiving preventive care and having medical homes were of lower SES, racial/ethnic minorities, publicly insured, and those with ≥ 2 other health conditions, indicating potential opportunities for targeted intervention to improve health equity. ..

The findings from this study are among all children with heart conditions, and may not be generalizable to children with CHDs specifically. Therefore, further research may be needed to examine prevalence of medical homes among children with CHDs and other acquired conditions separately. This will help researchers to further understand the barriers that may contribute to a children with specific heart conditions having a medical home.

Additionally, it is important to understand why certain socioeconomic factors are associated with receiving preventive care and having a medical home among children with heart conditions. For example, this study focused on a wide range of upstream social determinants

such as parental education-level, income, and insurance status (Braveman, Egerter, & Williams, 2011). However, it may be useful to research other constructs of the social determinants of health, particularly, an individual's social and community context as well as neighborhood and built environment (U.S. Department of Health and Human Services, 2018). These two constructs will allow researchers to examine the environment in which children with heart conditions are physically and socially in to better understand some barriers or advantages to receiving preventive care and having a medical home. Research should also examine whether health disparities exist for certain medical home components, i.e., are lower among children of lower SES and/or among racial/ethnic minorities. While this study examined socioeconomic factors using quantitative data analysis, it would be valuable to assess these factors using qualitative data analyses to obtain a deeper understanding. By expanding the literature about receiving preventive care and having a medical home among children with heart conditions, public health professionals will be able to improve public health and medical practice and policy to improve the quality of care and healthcare access among children with heart conditions.

Secondly, findings from our study revealed health disparities among racial and ethnic groups with heart conditions in regard to having a medical home. The Healthy People 2020 approach to the Social Determinants of Health Theoretical framework highlights the importance of cultivating healthy social and community context to improve the health of individuals (U.S. Department of Health and Human Services, 2018). Public health professionals can striving to improve health equity when designing interventions in public health practice. According to the Centers for Disease Control and Prevention (CDC), health equity is defined as equal health among all individuals without the effects of an individual's "social position or socially determined circumstance" (Braveman, 2003). The U.S. Department of Health and Human

Services similarly defines health equity as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage” (U.S. Department of Health and Human Services, 2019a). By striving for health equity in every racial and ethnic population reached through public health intervention, we as public health professionals will be closer to achieving the Health People 2030 overarching goal of “eliminating health disparities, achieve health equity, and attain health literacy to improve the health and well-being of all” (U.S. department of Health and Human Services, 2019b).Moreover, when designing interventions, it is important to ensure that they are culturally competent in order to achieve health equity among racial and ethnic populations. Thus, in context of this research study, targeting culturally competent interventions in clinics where racial and ethnic minority children with heart conditions receive care could ultimately increase the percent of US children with heart conditions in different racial and ethnic minority populations that have a medical home.

Our findings also showed that children with heart conditions and ≥ 2 other health conditions were less likely than children with no other health conditions to have a medical home. In addition, children with heart conditions, compared to those without, respectively, were less likely to have received all needed components of care coordination (63.8% and 73.0%; $p<0.05$ for both). Interventions that streamline communication among PCPs, cardiologists, and other physicians who care for children with heart conditions could ultimately improve quality of life. Identifying innovations in care coordination proven effective in other pediatric populations, such as children with medical complexities or chronic conditions, may help increase care coordination among children with heart conditions. Additionally, we found that children with heart conditions were as likely as those without heart conditions to have a medical home. Interventions that

increase medical homes for all children may increase prevalence among children with heart conditions.

Overall, while findings from our study were positive in regard to the prevalence of children with heart conditions receiving preventive care, our findings indicate more work needs to be done regarding increasing the number of children with heart conditions who have medical homes. The Social Determinants of Health theoretical framework was used to discover and understand the socioeconomic factors that may contribute to less than half of US children with heart conditions having a medical home. Further research and innovations in public health and clinical practice may increase medical homes and coordination of care, which may ultimately improve the health of the pediatric population with heart conditions.

References

Adams, S. H., Park, M. J., & Irwin, C. E., Jr. (2015). Adolescent and Young Adult Preventive Care. *American Journal of Preventive Medicine, 49*(2), 238-247. doi:10.1016/j.amepre.2015.02.022

American Academy of Pediatrics. (2002). Developmental surveillance and screening of infants and young children. *Pediatrics, 109*(1), 144-145.

American Academy of Pediatrics. (2014). 2014 Recommendations for Pediatric Preventive Health Care. *Pediatrics, 133*(3).

American Academy of Pediatrics. (2018). Key definitions. Retrieved from https://www.aap.org/en-us/professional-resources/practice-transformation/Pages/Key-Definitions.aspx

Antshel, K., Aneja, A., Strunge, L., Peebles, J., Fremont, W., Stallone, K., . . . Kates, W. (2007). Autistic spectrum disorders in velo-cardio facial syndrome (22q11.2 deletion). *Journal of Autistic and developmental disorder, 37*, 1776 –1786.

Antshel, K., Faraone, S., Fremont, W., Monuteaux, M., Kates, W., Doyle, A., . . . Biederman, J. (2007). Comparing ADHD in velocardiofacial syndrome to idiopathic ADHD. *Journal of Attention Disorders, 11*, 64-73.

Arth, A., Tinker, S., Simeone, R., Ailes, E., Cragan, J., & Grosse, S. (2017). Inpatient Hospitalization Costs Associated with Birth Defects Among Persons of All Ages — United States,2013. *MMWR Morb Mortal Wkly Rep, 66*, 41-46. doi:http://dx.doi.org/10.15585/mmwr.mm6602a1

Avendano, M., & Glymour, M. (2008). Stroke disparities in older Americans: Is wealth a more powerful indicator of risk than income and education. *Stroke, 39*, 1533-1540.

Ballweg, J., Wernovsky , G., & Gaynor, J. (2007). Neurodevelopmental outcomes following congenital heart surgery. *Pediatric Cardiology, 28*(126-133).

Bartley, M., & Plewis, I. (2002). Accumulated labour market disadvantage and limiting long-term illness: data from the 1971–1991 Office for National Statistics' Longitudinal Study. *International Journal of Epidemiology, 31*(2), 336-341. doi:https://doi.org/10.1093/ije/31.2.336

Beaudoin, A., Edison, L., E Introcaso, C., Goh, L., Marrone, J., Mejia, A., & Van Beneden, C. (2015). *Acute Rheumatic Fever and Rheumatic Heart Disease Among Children - American Samoa, 2011-2012* (Vol. 64).

Belay, E. D., Holman, R. C., Maddox, R. A., Foster, D. A., & Schonberger, L. B. (2003). Kawasaki syndrome hospitalizations and associated costs in the United States. *Public Health Rep, 118*(5), 464-469. doi:10.1093/phr/118.5.464

Bellinger, D. (2008). Are children with congenital cardiac malformations at increased risk of deficits in social cognition? *Cardiology Young*(18), 3-9.

Bethell, C. D., Read, D., & Brockwood, K. (2004). Using Existing Population-Based Data Sets to Measure the American Academy of Pediatrics Definition of Medical Home for All Children and Children with Special Health Care Needs. *Pediatrics, 113*, 1529-1537.

Braveman, P. (2003). Monitoring equity in health and healthcare: a conceptual framework. *Journal of Health, Population, and Nutrition, 21*(3), 181.

Braveman, P., Cubbin, C., Egerter, S., Williams, D., & Elsie, P. (2010). Socioeconomic Disparities in Health in the United States: What the Patterns Tell Us. *American Journal of Public Health, 100*, S186-S196. doi:10.2105/AJPH.2009.166082

Braveman, P., Egerter, S., & Williams, D. (2011a). The Social Determinants of Health: Coming of Age. *Annual Review of Public Health, 32*(1), 381-398.

Bru¨ne, M., & Bru¨ne-Cohrs, U. (2006). Theory of mind: evolution, ontogeny, brain mechanisms and psychopathology. *Neuroscience & Biobehavioral Reviews, 30*, 437-455.

Centers for Disease Control and Prevention. (2018a). Congenital Heart Defects. Retrieved from https://www.cdc.gov/ncbddd/heartdefects/data.html

Centers for Disease Control and Prevention. (2018b). Social Determinants of Health: know what affects health Retrieved from https://www.cdc.gov/socialdeterminants/index.htm

Chen, M., Riehle-Colarusso, T., Yeung , L., Smith, C., & Farr, S. (2018). Children with Heart Conditions and Their Special Health Care Needs — United States, 2016. *MMWR Morbidity and Mortality Weekly Report, 67*, 1045–1049. doi: http://dx.doi.org/10.15585/mmwr.mm6738a1

Child and Adolescent Health Measurement Initiative. (2016). The National Survey of Children's Health. Retrieved from http://www.childhealthdata.org

Child Trends Databank. (2014). Well-Child Visits. Retrieved from https://www.childtrends.org/indicators/well-child-visits

Connor, J. A., Kline, N. E., Mott, S., Harris, S. K., & Jenkins, K. J. (2010). The Meaning of Cost for Families of Children With Congenital Heart Disease. *Journal of Pediatric Health Care, 24*(5), 318-325. doi:10.1016/j.pedhc.2009.09.002

Cora, P., April, D., D., G. S., Tiffany, R.-C., S., O. R., Paul, T. J., . . . H., C. C. (2013). Hospitalizations, costs, and mortality among infants with critical congenital heart disease: How important is timely detection? *Birth Defects Research Part A: Clinical and Molecular Teratology, 97*(10), 664-672. doi:doi:10.1002/bdra.23165

Daly, M., Duncan, G., McDonough, P., & Williams, D. (2002). Optimal indicators of socioeconomic status for health research. *American Journal of Public Health, 92*, 1151-1157.

Downing, K., Oster, M., & Farr, S. (2017). Preparing adolescents with heart problems for transition to adult care, 2009-2010 National Survey of Children with Special Health Care Needs. *Congenital Heart Disease, 12*(4), 497-506. doi:https://doi.org/10.1111/chd.12476

Farr, S., Downing, K., Riehle-Colarusso, T., & Abarbanell, G. (2018). Functional limitations and educational needs among children and adolescents with heart disease. *Congenital Heart Disease*, 1-7. doi:https://doi-org.proxy.library.emory.edu/10.1111/chd.12621

Fernandes, S., & Sanders, L. (2015). Patient-centered medical home for patients with complex congenital heart disease. *Current opinion in Pediatrics, 27*(5), 581-586.

Fuller, S., Nord, A., Gerdes, M., Wernovsky, G., Jarvik, G., Bernbaum, J., . . . Gaynor, J. (2009). Predictors of impaired neurodevelopmental outcomes at one year of age after infant cardiac surgery. *European Journal of Cardio-Thoracic Surgery, 36*, 40 – 47.

Gaynor, J., Wernovsky, G., Jarvik, G., Bernbaum , J., Gerdes, M., Zackai, E., . . . Spray, T. (2007). Patient characteristics are important determinants of neurodevelopmental outcome at one year of age after neonatal and infant cardiac surgery. *Journal of Thoracic and Cardiovascular Surgery, 133*, 1344 –1353.

Gilboa, S. M., Devine, O. J., Kucik, J. E., Oster, M. E., Riehle-Colarusso, T., Nembhard, W. N., . . . Marelli, A. J. (2016). Congenital Heart Defects in the United States: Estimating the Magnitude of the Affected Population in 2010. *Circulation, 134*(2), 101-109. doi:10.1161/circulationaha.115.019307

Hartman RJ, Rasmussen SA, Botto LD, Riehle-Colarusso T, Martin CL, Cragan JD, & Shin M, C. A. (2011). The contribution of chromosomal abnormalities to congenital heart defects: a population-based study. . *Pediatric Cardiology, 32*(8), 1147-1157.

Herd, P., Goesling, B., & House, J. (2007). Socioeconomic position and health: the differential effects of education versus income on the onset versus progression of health problems. *Journal of Health and Social Behavior, 48*, 223-238.

Homer, C. J., Klatka, K., Romm, D., Kuhlthau, K., Bloom, S., Newacheck, P. W., . . . Perrin, J. M. (2008). A Review of the Evidence for the Medical Home for Children With Special Health Care Needs. *Pediatrics, 122*(4), e922-e937. doi:10.1542/peds.2007-3762

Hughes, D. C., Duderstadt, K. G., Soobader, M. P., & Newacheck, P. W. (2005). Disparities in children's use of oral health services. *Public Health Reports, 120*(4), 455-462.

Hultman, C., Spare´n, P., & Cnattingius, S. (2002). Perinatal risk factors for infantile autism. *Epidemiology, 13*, 417-423.

Hummer, R., & Lariscy, J. (2011). *International handbook of adult mortality, International Handbooksof Population 2* (R. Rogers & E. Crimmins Eds.). New York, New York City: Springer Science+Business Media B.

Kuo, H. C., Chang, W. C., Wang, L. J., Li, S. C., & Chang, W. P. (2016). Association of Attention deficit hyperactivity disorder and Kawasaki disease: a nationwide population-based cohort study. *Epidemiol Psychiatr Sci, 25*(6), 573-580. doi:10.1017/S2045796015000840

Lantin-Hermoso, M. R., Berger, S., Bhatt, A. B., Richerson, J. E., Morrow, R., Freed, M. D., & Beekman, R. H. (2017). The Care of Children With Congenital Heart Disease in Their Primary Medical Home. *Pediatrics, 140*(5).

Larson, K., & Halfon, N. (2010). Family Income Gradients in the Health and Health Care Access of US Children. *Maternal and Child Health Journal, 14*(3), 332-342. doi:10.1007/s10995-009-0477-y

Leganger, A., & Kraft, P. (2003). Control constructs: Do they mediate the relatin between educational attainment and health behvavior? *Journal of Health Psychology, 8*(3), 361-372.

Lin, C.-W., Romley, J. A., & Carlin, C. (2018). The Relationship Between the Patient-Centered Medical Homes, Healthcare Expenditures, and Quality of Care Among Children with Special Health Care Needs. *Maternal and Child Health Journal*. doi:10.1007/s10995-018-2572-4

Lyon, M., Kuehl, K., & McCarter, R. (2006). Transition to adulthood in congenital heart disease: missed adolescent milestones. *Journal of Adolescent Health, 39*, 121-124.

Marino, B. S., Lipkin, P. H., Newburger, J. W., Peacock, G., Gerdes, M., Gaynor, J. W., . . . Mahle, W. T. (2012). Neurodevelopmental Outcomes in Children With Congenital Heart Disease: Evaluation and Management. *A Scientific Statement From the American Heart Association*. doi:10.1161/CIR.0b013e318265ee8a

McClung, N., Glidewell, J., & Farr, S. L. (2018). Financial burdens and mental health needs in families of children with congenital heart disease. *Congenit Heart Dis, 13*(4), 554-562. doi:10.1111/chd.12605

Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2002). The Medical Home. *Pediatrics, 110*(1), 184-186. doi:10.1542/peds.110.1.184

Mirowsky, J., & Ross, C. (1998). Education, personal control, lifestyle and health - A human capital hypothesis. *20*(4), 415-449.

Morris, L. S., Schettine, A. M., Roohan, P. J., & Gesten, F. (2011). Preventive Care for Chronically Ill Children in Medicaid Managed Care. *The American Journal of Managed Care, 11*, e435-442.

Mosquera, R. A., Avritscher, E., Samuels, C. L., Harris, T. S., Pedroza, C., Evans, P., . . . Tyson, J. E. (2014). Effect of an Enhanced Medical Home on Serious Illness and Cost of Care Among High-Risk Children With Chronic Illness: A Randomized Clinical Trial. *Journal of American Medical Association, 312*(24), 2640-2648. doi:10.1001/jama.2014.16419

Mulvihill, B. A., Altarac, M., Swaminathan, S., Kirby, R. S., Kulczycki, A., & Ellis, D. E. (2007). Does Access to a Medical Home Differ According to Child and Family Characteristics, Including Special-Health-Care-Needs Status, Among Children in Alabama? *Pediatrics, 119*(Supplement 1), S107.

Mussatto, K., & Tweddell, J. (2005). Quality of life following surgery for congenital cardiac malformations in neonates and infants. *Cardiology Young, 15*, 174-178.

National Institute of Health. (2018). 22q11.2 deletion syndrome.Retrieved from https://ghr.nlm.nih.gov/condition/22q112-deletion-syndrome#statistics

National Survey of Children's Health. (2011-12). Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved from www.childhealthdata.org

Newacheck, P. W., Hung, Y. Y., Jane Park, M., Brindis, C. D., & Irwin, C. E. (2003). Disparities in Adolescent Health and Health Care: Does Socioeconomic Status Matter? *Health Services Research, 38*(5), 1235-1252. doi:10.1111/1475-6773.00174

Niklasson, L., Rasmussen, P., O´skarsdo´ttir , S., & Gillberg , C. (2009). Autism, ADHD, mental retardation and behavior problems in 100 individuals with 22q11deletion syndrome. *Research in Developmental Disabilities, 30*, 763–773.

Oster, M. E., Lee, K. A., Honein, M. A., Riehle-Colarusso, T., Shin, M., & Correa, A. (2013). Temporal Trends in Survival Among Infants With Critical Congenital Heart Defects. *Pediatrics*, 2012-3435.

Pierpont, M., Basson, C., Benson, D. J., Gelb, B., Giglia, T., Goldmuntz, E., . . . Webb, C. (2007). Genetic basis for congenital heart defects: current knowledge: a scientific statement from the American Heart Association Congenital Cardiac Defects Committee, Council on Cardiovascular Disease in the Young. *Circulation, 115*, 3015–3038.

Razzaghi, H., Oster, M., & Reefhuis, J. (2015). Long-Term Outcomes in Children with Congenital Heart Disease: National Health Interview Survey. *The Journal of Pediatrics, 166*(1), 119-124. doi:https://doi.org/10.1016/j.jpeds.2014.09.006.

Riehle-Colarusso, T., Autry, A., Razzaghi, H., Boyle, C. A., Mahle, W. T., Van Naarden Braun, K., & Correa, A. (2015). Congenital Heart Defects and Receipt of Special Education Services. *Pediatrics, 136*(3), 496-504. doi:10.1542/peds.2015-0259

Seattle Children's Hospital. (2018). Kawasaki Disease. Retrieved from http://www.seattlechildrens.org/medical-conditions/heart-blood-conditions/kawasaki-disease/

Shumskiy, I., Richardson, T., Brar, S., Hall, M., Cox, J., Crofton, C., . . . Berry, J. (2018). Well-Child Visits of Medicaid-Insured Children with Medical Complexity. *Journal of Pediatrics*. doi:0.1016/j.jpeds.2018.04.003

Singh, G. K., Strickland, B. B., Ghandour, R. M., & van Dyck, P. C. (2009). Geographic Disparities in Access to the Medical Home Among US CSHCN. *Pediatrics, 124*(Supplement 4), S352.

Stevens, G. D., & Kim, A. Y. (2016). National Trends in Indicators of a Medical Home for Children. *Maternal and Child Health Journal, 20*(3), 730-739. doi:10.1007/s10995-015-1902-z

Strickland, B. B., Singh, G. K., Kogan, M. D., Mann, M. Y., van Dyck, P. C., & Newacheck, P. W. (2009). Access to the Medical Home: New Findings From the 2005-2006 National Survey of Children With Special Health Care Needs. *Pediatrics, 123*(6), e996-e1004. doi:10.1542/peds.2008-2504

Sznajer, Y., Keren, B., Baumann, C., Pereira, S., Alberti, C., Elion, J., . . . Verloes, A. (2007). The spectrum of cardiac anomalies in Noonan syndrome as a result of mutations in the PTPN11 gene. *Pediatrics, 119*, e1325– e1331.

Tabbutt, S., Nord, A., Jarvik, G., Bernbaum, J., Wernovsky, G., Gerdes, M., . . . Gaynor, J. (2008). Neurodevelopmental outcomes after staged palliation for hypoplastic left heart syndrome. *Pediatrics, 121*, 476-483.

Tom, J. O., Mangione-Smith, R., Grossman, D. C., Solomon, C., & Tseng, C. W. (2013). Well-child care visits and risk of ambulatory care-sensitive hospitalizations. *Am J Manag Care, 19*(5), 354-360.

Tom, J. O., Tseng, C. W., Davis, J., Solomon, C., Zhou, C., & Mangione-Smith, R. (2010). Missed well-child care visits, low continuity of care, and risk of ambulatory care-sensitive hospitalizations in young children. *Arch Pediatr Adolesc Med, 164*(11), 1052-1058. doi:10.1001/archpediatrics.2010.201

U.S. Department of Health and Human Services. (2018). Social Determinants of Health. Retrieved from https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health

U.S. Department of Health and Human Services. (2019a). Disparities.Retrieved from https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities#6

U.S. department of Health and Human Services. (2019b). Health People 2030 Retrieved from https://www.healthypeople.gov/2020/about-healthy-people/development-healthy-people-2030/framework

USF Benioff Children's Hospital. (2019). Acquired Heart Disease.Retrieved from https://www.ucsfbenioffchildrens.org/education/acquired_heart_disease/

Van Cleave, J., & Davis, M. M. (2008). Preventive care utilization among children with and without special health care needs: associations with unmet need. *Ambul Pediatr, 8*(5), 305-311. doi:10.1016/j.ambp.2008.04.003

Van Cleave, J., Okumura, M. J., Swigonski, N., O'Connor, K. G., Mann, M., & Lail, J. L. Medical Homes for Children With Special Health Care Needs: Primary Care or Subspecialty Service? *Academic Pediatrics, 16*(4), 366-372. doi:10.1016/j.acap.2015.10.009

Walker, R., Gauvreau, K., & Jenkins, K. (2004). Health-related quality of life in children attending a cardiology clinic. *Pediatric Cardiology, 25*, 40-48.

Wang, L. J., & Kuo, H. C. (2017). Cognitive Development After Kawasaki Disease- Clinical Study and Validation Using a Nationwide Population-Based Cohort. *Circ J*. doi:10.1253/circj.CJ-17-0557

Wier, M., Yoshida, C., Odouli, R., Grether, J., & Croen, L. (2006). Congenital anomalies associated with autism spectrum disorders. *Developmental Medicine & Child Neurology, 48*, 500 –507.

Young, P. C., Shyr, Y., & Schork, M. A. (1994). The Role of the Primary Care Physician in the Care of Children with Serious Heart Disease. *Pediatrics, 94*(3), 284.