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Barriers to Patient Centered Medical Homes in Adults with Congenital Heart Disease

Christine Peverini

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Georgia State University

Abstract

Purpose: As patients with adult congenital heart disease (ACHD) age, they encounter age associated comorbidities, congruous with the general population. At their ACHD appointments, they present with untreated medical problems associated with asthma, diabetes, contraception, and respiratory infections. This project seeks to identify barriers associated with establishing care in patient-centered medical home (PCMH); understand current primary care utilization and identify patient perceptions contributing to lack of follow up in primary care.

Methods: An 84-question validated survey completed electronically by patients (> 18 years) presenting at the outpatient congenital cardiac clinic between September 12, 2019 to November 15, 2019 was used to evaluate barriers to care, patient perceptions on healthcare and healthcare utilization patterns.

Results: Survey responses filled out by 30 participants with a mean age 44 ±16.9 years were used to evaluate barriers to care. 80% (n=24) were not aware of a PCMH model; but 77% (n=23) were willing to drive 1-50 miles to access a primary care physician. All participants had access to PCMH within 20 miles of their residence. In a multivariate model, BCQ scores were not statistically significant when accounting for insurance status, CHD severity, or having regular primary care. 93% felt their ACHD cardiologist would inform them if they needed to see someone else. 43% expressed distrust for providers not trained in their heart condition. The largest barriers to care were taking time off work (24%), healthcare costs (23%), getting a thorough exam (23%), meeting the needs of other family members (20%), reaching the office by phone (17%), appointment lag time (17%), long waiting room time (17%), lack of communication within the healthcare system (17%), and getting questions answered (17%).

Conclusions: This project illustrated a lack of awareness of PCMHs in ACHD patients. Health insurance status, having a primary care provider, ethnicity and education level did not have a statistically significant effect on BCQ scores. However, responses to the survey yielded valuable information for improving care for this population.

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Background and Significance

According to the Centers for Disease Control and Prevention (CDC), in the United States congenital heart disease (CHD) affects approximately one percent of the population per year or approximately 40,000 live births (Centers for Disease Control and Prevention, 2016). In 2010, there were 1 million children and 1.4 million adults living with CHD. Twenty to thirty percent of those born with CHD have other physical, cognitive or developmental disorders (Centers for Disease Control and Prevention, 2016). Due to advances in medical technologies and surgical innovations we are living in a time when the number of adults with CHD outnumbers children living with CHD (Webb et al., 2015). Adult congenital cardiology is a relatively young field and best practice models are still being formed and implemented. However, with "a prevalence of 8-9 per 1000 live births" (Ntiloudi et al., 2016, p. 269) it remains less common than atherosclerotic heart disease (Barquera et al., 2015) and therefore training in atherosclerotic disease remains the primary focus of internal medicine and cardiology fellowship programs. Since December 2012, fellowship programs in adult congenital cardiology became two-year fellowships (Stout et al., 2015) and the first board certification in adult congenital heart disease was available in October 2015 (American Board of Pediatrics, 2014). Despite increases in training and fellowship programs for adult congenital cardiologists, the number of pediatric cardiologists continues to outnumber their adult congenital counterparts (Avila et al., 2014). A shortage of qualified providers to care for this population remains. For many reasons, it is well documented that "ACHD patients often find themselves in 'no man's land' when it comes to a medical home" (Kirkpatrick, Kim, & Kaufman, 2012, p. 268). As this population ages, they face common non-cardiac issues such as diabetes, asthma, family planning and depression (Seckeler et al., 2015). Congenital cardiology appointment time is often spent coordinating care for primary care diagnoses. Many adolescents fail to make the transition to adult care (Gurvitz et al., 2013) which

makes it a challenge to meet the complex needs of this subset of the population. However, it has been shown that patients continue to utilize primary care through all age groups (Mackie et al., 2009). Furthermore, it has been shown that CHD patients hospitalized for non-cardiac issues incur higher costs than age matched non-CHD patients (Seckeler et al., 2015). The non-cardiac issues include common primary care diagnoses such as asthma, diabetes, obstructive sleep apnea, hypothyroidism and cancer screenings (Sillman et al., 2017). Primary care also provides an appropriate setting for antibiotic prescription for subacute bacterial endocarditis prophylaxis, anticoagulation management, primary prevention of influenza, pneumonia and hepatitis A/B via vaccination, measurement of uric acid and treatment of gout, pregnancy counseling and contraception management (Gurvitz, Marelli, Mangione-Smith, & Jenkins, 2013). A model of advancing population healthcare advocates for organizing primary care around groups of patients with similar needs has been proposed by Porter, Pabo, and Lee (2013).

Patient-centered medical homes (PCMH) have been shown to improve healthcare outcomes in populations with chronic illness. Improvement in medication compliance as a measure of healthcare, decreased hospital admissions, decreased ER utilization and improved patient satisfaction have all been demonstrated in the chronically ill in a PCMH (Mosquera et al., 2014). In fact, the Adult Congenital Heart Association (ACHA) has recommended a policy promoting the establishment of medical homes for ACHD patients (ACHA, 2016).

Problem Statement:

Barriers to CHD care are numerous and include limited access to care, developmental disability that impedes learning and self-care as well as lack of sufficient reimbursement for additional time required to coordinate care in this population (Berens & Peacock, 2015). However, there is paucity of information available on barriers to care and patient perceptions that contribute to lack of follow-up in primary care for adults with congenital heart disease.

Clinical Question

What is the current practice of adults with CHD as it relates to perceived primary care needs and utilization for individuals who received care at a comprehensive cardiac care center in the fall of 2018? What barriers prevent establishment within a patient-centered medical home (PCMH)?

Synthesis of Evidence

Search Strategy

A literature search was performed using a university's Galileo databases which included: Pubmed, ScienceDirect, Academic Search Complete, and CINAHL plus. The database search was limited to articles in Health & Medicine and Nursing and Allied Health. Key search terms included: medical home, adult congenital heart disease, patient centered care, cardiology, chronic disease and PCMH, heart, primary care, cost of congenital heart disease, and barriers to care. Articles were limited to those published in English between 2012-2018. Cochrane Collaboration was also searched but did not yield any CHD/medical home results. The search yielded 696 articles. Articles were included if they were deemed pertinent to both congenital heart disease and primary care. Articles focusing on increased non-cardiac morbidities associated with congenital heart disease or utilization of pediatric care systems for adult health concerns were included. Abstracts were reviewed and reports on neonatal screening, imaging modalities, specific cardiac medications and catheter-based interventional techniques were excluded. Initially, articles were limited to adults (18 years or older); however, given the scarcity of information pediatric articles relevant to the clinical question were subsequently included. After closely reviewing 112 abstracts a total of 46 articles were selected as having applicability to the clinical questions. Additionally, several older articles were found during bibliography reviews and were utilized as they were recognized to be pertinent to the clinical

question. Ten research studies were evaluated using evidence matrix tables to determine the strength of evidence for using patient-centered medical home for adults with congenital heart disease. Each study was examined to define the clinical question, study design, sample, measurement and results. Level of evidence (LOE) was then determined based on the Evidence hierarchy with level I being the highest LOE based on systematic reviews and LOE VII being based on expert consensus or case reports (Polit & Beck, 2017). Evidence matrices can be found in Appendix A. Table 1 summarizes the search terms, limits, databases and other sources applied during the literature review.

Table 1
Search Strategy

Search Criteria	**Key Words**
Key Search Terms	Adult Congenital Heart Disease, Patient Centered Medical Home (PCMH), Chronic heart, medical homes, patient centered care, cost of congenital heart disease, spectrum, primary care
Years /Language	2012-2018 / English
Age	Adult (age 18 and up)
Search Engines	Georgia State University Galileo, Google Scholar
Databases	Pubmed, CINAHL plus, Academic Search Complete, Science Direct
Government &Regulatory Agencies	Centers for Disease Control and Prevention, Cochrane Collaboration
Other	Bibliographies of articles deemed pertinent to clinical question

Benefits to PCMH Enrollment

Even though there is conflicting evidence regarding the benefits of a patient-centered medical home for everyone, studies consistently demonstrate advantage to enrollment in a patient-centered medical home for populations with chronic health conditions (Mosquera et al, 2014). A large retrospective cohort study was carried out by Lauffenburger et al. (2017)

Researchers utilizing insurance claims data analyzed the effect on medication compliance as new medication therapy was initiated in a patient-centered medical home. The patient population included adults age 18 or greater and therapy with an oral hypoglycemic, antihypertensive or lipid lowering medication started between 1/1/2011 and 12/31/2013. Adherence was measured for 12 months after new treatment was initiated. The results indicated that receipt of care in a National Committee for Quality Assurance (NCQA) certified PCMH is associated with improved adherence among patients beginning treatment for common chronic conditions. It was estimated that on average, there was a 2-3% increase in adherence for patients receiving care in a NCQA certified PCMH as compared to those initiating care in other practices (Lauffenburger et al., 2017).

Mosquera et al., conducted a randomized clinical trial to evaluate the effect of a medical home among high-risk children with chronic illnesses between March 2011 and February 2013. This was compared to children receiving usual care. Children were aged 18 or younger with a chronic illness living within 1 hours of the University of Texas, Houston (UTH). Primary outcomes included children with serious illness (defined as death, ICU admission or hospital stay > 7 days), and costs from a health system perspective. The analysis showed benefit of the PCMH to reducing serious illness and cost in high risk children with chronic health conditions [10 serious illnesses per 100 child years vs 22 for the usual care, (Mosquera et al., 2014)]. Examination of Medicaid billings were utilized to compare the groups (Mosquera et al., 2014).

Healthcare Utilization of ACHD Patients

A feasibility study implemented by Ellison et al. (2013) utilized descriptive analysis via retrospective review of patient diagnosis codes to identify ACHD patients in the United Kingdom. The analysis showed a disparity between optimal and current care of ACHD patients. Identification of ACHD patients by diagnosis code and utilization of a toolkit in the primary care

setting could help improve quality, timeliness of care, patient experience and overall health (Ellison et al., 2013). This study illuminates the need for standardized coding of congenital heart conditions. Currently, there are multiple International Classification of Diseases (ICD) codes for CHD. Early identification of congenital patients in a primary care setting could provide a means of following protocols designed to provide for optimal health (Ellison et al., 2013).

A retrospective analysis of healthcare resource utilization for patients with single ventricles that were hospitalized for non-cardiac reasons was performed by Seckeler et al. (2015). The study cohort included all admissions from January 2011 to November 2014. The study was stratified into two groups: ages 18-29 years and ages 30-40. The most commonly identified non-cardiac diagnoses included acute kidney injury, asthma, chronic kidney disease, liver disease, gastroesophageal reflux syndrome, hypothyroidism, migraine headache, obstructive sleep apnea, obesity, pneumonia, urinary tract infection and depressive disorder. The younger cohort of patients averaged the same length of stay in the hospital as the age-matched non-CHD patients but incurred higher costs for several diagnoses. The cohort of 30-40 year olds had longer length of stay and higher costs for several diagnoses compared to the age-matched non-CHD cohort. These findings suggest several non-cardiac comorbidities which would make excellent primary care quality indicators for this complex subset of the ACHD population (Seckeler et al., 2015).

Another study aimed at evaluating the patterns of healthcare utilization and costs associated with CHD care in young adults was conducted by Lu, Agrawal, Lin and Williams, 2014. This was also a descriptive retrospective study reviewing inpatient admissions on CHD patients in California who were age 10-29 years of age in 2005-2009. Three California databases containing inpatient admission information was reviewed. It was found that young adults use fewer healthcare resources given the natural history of congenital heart disease which results in

fewer surgeries in that time. However, more frequent (less costly) admissions occurred mostly for heart failure or arrhythmias. Often, these patients present to the emergency department (ED) as the incidents are unexpected and require urgent care. There is a 35% higher incidence in utilization of the ED from adolescence to young adulthood. This data suggests that access to care is a significant barrier to care in young adults who age out of Medicaid and/or lose status as a dependent under their parents' insurance plans (Lu, Agrawal, Lin and Williams, 2014).

Aging and ACHD Population

Khairy et al., (2010) has shown that mortality trends in the CHD population has shifted towards adulthood. This descriptive retrospective study was an open population-based study of CHD patients in Quebec, Canada from July 1987 to June 2005. A steady increase in age at death and decreasing mortality has been shown. Infants showed a 77% decrease in mortality and adults with CHD also showed reductions in mortality which paralleled those seen in the general population. Factors contributing to improved survival of infants include increased prenatal diagnosis and early detection of heart defects as well as surgical and interventional procedure advances. In the adolescent, earlier detection, diagnosis and refined criteria for surgical or interventional procedures contributed to improved survival. In those over age 65 years co-morbid conditions such as chronic renal disease, heart failure, myocardial infarction and malignant cancer were associated with mortality.

Potential barriers that have been identified in the literature include issues with access to healthcare, developmental disability, allotment of time for ACHD providers to coordinate care, reimbursement, utilization of a specialty service to provide primary care (Kirkpatrick, Kim, & Kaufman, 2012), and lack of trained ACHD providers (Avila et al., 2014). Breaks in medical care may be associated with adverse outcomes. ACHD patients with gaps in care are more likely to need urgent cardiac procedures or have undertreated cardiac conditions. Gurvitz et al., (2013)

conducted a multicenter prospective cross-sectional analysis that identified gaps in CHD care which typically occur at the age of transition (~ 20 years old) and is more common in those with mild to moderate CHD. The sample consisted of 922 subjects age 18 or older who presented for a new patient visit at one of 12 ACHD centers in the US. Questionnaire and interview were administered at the first visit and continuous and categorical variables were obtained and analyzed appropriately. Return to CHD care was often prompted by a new symptom or recommendation from another healthcare provider (Gurvitz et al., 2013). Berens and Peacock (2015) conducted a retrospective qualitative descriptive analysis which outlined the development and implementation of a Transition Medicine Clinic (TMC) for adolescents and young adults with chronic childhood conditions. Among the common primary diagnoses were Down's syndrome, genetic conditions and autism (Berens & Peacock, 2015). Challenges included publicly-funded healthcare issues with 80% of patients receiving Medicaid. Also, more than half had an intellectual disability. Analysis of resource utilization showed that physicians and support staff familiar with the challenges mentioned were needed. Significant time and effort outside of routine allotted office visits were required to coordinate care (Berens & Peacock, 2015).

A paper by Kirkpatrick, Kim and Kaufman in 2012 described ethical priorities in the aging ACHD population. Development of "adult" heart diseases such as hypertension and coronary artery disease compound the challenges faced by the congenital heart population. The ACHD provider is not only a specialty consultant but functions additionally as a primary care provider in the adult lifespan. Behavioral concerns such as depression, anxiety and hyperactivity disorders are more common. Physical debilitation and absenteeism complicate education and employment opportunities. Access to healthcare as they transition to adult facilities is a common issue faced by many with chronic childhood illness, particularly for those from medically

underserved communities. Access to psychiatric services and social workers is clearly demonstrated in this population (Kirkpatrick, Kim, & Kaufman, 2012).

Walsh et al., (2012) was a sentinel health policy statement on the use of PCMH in cardiology. While this article focused on elements of patient-centered care pertinent to cardiology and contained statements acknowledging cognitive impairment and the potential need to involve family members in patient care, it was clear this article was aimed at the older general cardiac population. There was no mention of caring for adults with congenital heart disease. However, the authors did realize that a significant barrier to patient-centered care was financial reimbursement for the increased time needed to coordinate care that is patient-centered. Additionally, this article recognizes the general cardiology physician shortage as a barrier to high quality patient centered care (Walsh et al., 2012) but does not acknowledge the current shortage of trained adult congenital cardiologists who are currently being asked to provide personal frequent surveillance visits.

Another sentinel article by Gurvitz, Marelli, Mangione-Smith and Jenkins in 2013 listed quality indicators found to improve care for adults with congenital heart disease. There were no prior quality indicators for the measurement of care provided to ACHD patients. The working groups developed quality assessment tools for 6 common congenital conditions. These conditions include: secundum atrial septal defect, coarctation of the aorta, Eisenmenger syndrome, Fontan palliation, transposition of the great arteries and Tetralogy of Fallot. These consensus guidelines were written with the aim of standardizing care based on best available evidence (Gurvitz, Marelli, Mangione-Smith, & Jenkins, 2013).

In summary, studies demonstrate benefit to the use of a PCMH when utilized in the setting of chronic health conditions with level of evidence supporting use of 2-4 via randomly controlled clinical trials and several cohort studies. Descriptions of barriers to ACHD care in a

medical home was primarily based on systematic review or single descriptive and qualitative studies thus yielding level of evidence of 5-6. However, given that ACHD care is still developing the current evidence was utilized and sentinel papers written by experts in ACHD care have been referenced.

Conceptual Framework and Theory

Nursing Theory and Framework

The question this project will answer is: What is the current practice of adults with CHD as it relates to perceived primary care needs and utilization for individuals who received care at a local comprehensive cardiac care center in the fall of 2018? What barriers prevent establishment within a patient-centered medical home (PCMH)? Using a framework to guide the process of translating evidenced-based research into practice supports the doctoral project by systematically building on a solid foundation. Nursing theories and conceptual frameworks provide the scaffoldings where one may build credible evidence illuminating a particular health concern and thereby creating an environment primed for change.

In congenital cardiology, the clinical problem triggering this question is the frequency with which congenital cardiac providers encounter patients who request management of their non-cardiac diagnoses due to lack of primary care. The Adult Congenital Heart Association has prioritized helping patients with ACHD establish with a PCMH (ACHA, 2016). Promoting establishment in a patient-centered medical home is listed as a criterion for accreditation as an ACHA/ACHD comprehensive care center (ACHA, 2016). There is evidence that establishing a PCMH for those with chronic long-term conditions results in decreased hospital admissions, decreased ER utilization and improved patient satisfaction (Lerner & Klitzner, 2017). Other aspects of the PCMH model include improved patient access, collaboration among providers and comprehensive care (Lerner & Klitzner, 2017).

Betty Neuman's systems model is a nursing theory that presents an excellent framework for ACHD health care and the need for a patient centered medical home. The systems model sees the patient as an open system responding to internal and external stressors (Neuman & Reed, 2007). It is a holistic model which considers the physiological, psychological, sociocultural, spiritual and developmental aspects of an individual (Jukes & Spencer, 2007). Neuman's model seeks optimal patient stability which is highly personalized based on stressors unique to each individual. The patient constantly exchanges energy through interactions with internal and external stressors and the health outcome rests along a continuum between wellness and illness (Neuman & Reed, 2007). Her model considers prevention to be an intervention that is valuable to maintaining wellbeing. When the system needs are met, the system is balanced in a state of wellness. When needs are unmet, illness exists (Neuman & Reed, 2007). Once actual or potential stressors are identified, interventions are aimed at helping restore or maintain the balance of the system (Neuman, Newman & Holder, 2000). ACHD is unique in that individuals with the same congenital defect have differing levels of optimal stability and exhibit highly variable responses to stressors. Neuman's model also lends itself easily to utilizing the PCMH model given both are patient centered, value the client's perception of personal needs and encourage a healthcare partnership focused on meeting those needs (Neuman & Reed, 2007).

Neuman's model contains elements of primary, secondary and tertiary prevention to actual or potential stressors (Neuman, Newman & Holder, 2000). The role of a PCMH would be useful in providing early recognition of common maladies in ACHD such as arrhythmias, heart failure, obesity, liver fibrosis and depression (Ntiloudi et al., 2016). Examples of primary prevention measures would include providing hepatitis A/B vaccinations to prevent potential threat of liver injury as well as counsel to avoid hepatotoxic substances such as alcohol, herbal supplements and certain medications in susceptible patients (American Heart Association

Scientific Statement [AHA], 2017). Instructions on diet and exercise to reduce complications from obesity also fall into the primary prevention category. Secondary prevention occurs at the time of actual stressor (Newman & Fawcett, 2011) and would include active treatment of arrhythmias, heart failure exacerbations, illnesses, treatment of hepatitis C infection and management of actual complications during pregnancy (Ntiloudi et al., 2016). Tertiary prevention includes follow up after the stressor and occurs during the healing process. An example of this includes follow-up visits. Neuman's model also allows for complex relationships between stressors and recognizes that each individual has unique factors influencing this response. These factors can be physiological, sociocultural, spiritual, and developmental (Neuman & Reed, 2007). Genetic syndromes may be accompanied by congenital heart defects (Ko, 2015). Each syndrome impacts specific physiological responses and susceptibilities that manifest differently in those with the same heart defect (Kirkpatrick, Kim, & Kaufman, 2012). This population has a high proportion of individuals with developmental delay and some require caretakers for life (American Heart Association, 2012). Caregivers play an important role in assessment of those with developmental delay who are not able to articulate relevant information. In those instances, patient-centered care would focus on needs important to the individual and their caregiver.

Conventional nursing views the individual as a whole and therefore the nurse is well positioned as a health care advocate to influence all variables throughout the life span. Nurses armed with intimate knowledge of the health systems are in a key position to evaluate and improve responses to stressors thus aiding achievement of an optimal state of wellness (Neuman & Fawcett, 2011). The use of the patient-centered medical home model has been shown to reduce emergency room visits, decrease hospital admissions and improve satisfaction in patients with chronic health conditions (Lerner & Klitzner, 2017).

An understanding of congenital heart disease and the long-term sequelae for prior cardiac interventions is necessary as this population continues to age. However, utilizing congenital cardiologists to address common non-cardiac health conditions in this population is neither sustainable nor advisable. The number of ACHD patients already exceeds the capacity of specialist to provide for congenital cardiac care (Lane, 2012). Access to a patient-centered medical home will help balance wellness and the adult dimensions of ACHD patient with associated complexities. However, understanding the current perceived primary care needs and barriers to establishing in a PCMH are fundamental first steps in addressing and improving care in this growing population. Neuman's systems theory allows for the interplay of the multiple factors involved in the complex adult congenital population. It also provides a framework for working with the numerous psychosocial and developmental factors often associated with individuals in this population.

Methodology

This was a quantitative study utilizing Research Electronic Data Capture® (REDCap) online to collect responses to the Barriers to Care Questionnaire (BCQ); responses to patients perceived healthcare needs and current healthcare utilization patterns. Goals of this quality improvement project were to describe current primary care utilization patterns in adults with congenital heart disease (CHD), understand their perceived need of primary care services and identify barriers to establishment in a medical home.

Setting

An outpatient congenital cardiac clinic accredited as a comprehensive care center by the Adult Congenital Heart Association (ACHA) located in a large metropolitan area in the Southeast United States. The clinic sees an average of 3100 patient visits per year. The clinic operates Monday through Friday from 8:00 am to 5:00 pm and is staffed by 3 registered nurses,

two advanced practice providers and 5 congenital cardiologists, a full time licensed clinical social worker and a medical assistant. The clinic is also staffed by two sonographers and has two designated echocardiography rooms with three designated echocardiogram reading stations. The front desk is staffed by 3 to 4 attendants assigned to check in clients into all cardiac clinics, including the congenital cardiac clinic. There are two full-time administrative assistants and one dedicated check-out attendant who facilitate referrals and follow-up appointments. A registered nurse navigator facilitates new-patient referrals and coordinates a weekly surgical conference. The program has two Accreditation Council for Graduate Medical Education (ACGME) ACHD fellowship positions. The two fellows training on both the inpatient and outpatient care. The practice is affiliated with three area teaching hospitals affiliated with a medical school. The outpatient practice has two locations; the study was only conducted at the primary campus location. Clinic volume varies widely depending on the number of providers in clinic on a particular day and ranges from 10-35 patients who are seen in 4-6 rooms. Room availability varies due to clinic shared space arrangements. Routinely, all patients undergo an electrocardiogram on arrival as well as blood pressure and oxygen saturation readings in both upper extremities. The practice accepts commercial insurance, Medicaid and the uninsured (upon charity care arrangement).

Recruitment

Participants were approached by the Collaborative Institutional Training Initiative (CITI) certified student investigator at their outpatient visit between September 12, 2018 and November 15, 2018 following appointment check-in. Willing participants were provided a brief description of the survey by the student investigator and offered the option of completing the survey while in clinic by electronic tablet or having the survey link emailed for completion on their personal

electronic device. The survey took no longer than 20 minutes to complete. No incentives for participation were utilized.

Georgia State University's institutional review board approved the informed consent form on September 7, 2018. Informed consent was obtained electronically at the time of the survey and was captured electronically via REDCap by clicking the 'yes' in the appropriate field. Participants were able to print or save a copy of the consent if they desired. The student investigator is an employee of the healthcare facility from which participants were recruited.

After meeting inclusion criteria, participants were informed that participation was voluntary and had no effect upon receipt of care or the quality of care which they received. They were advised of their freedom to withdraw from study participation at any time. Secondary data obtained in the survey were confirmed at the time of chart review (if available) and included: specific congenital diagnoses, non-cardiac diagnoses, gender identity, age, race, BMI, ethnicity, insurance information, and residential zip code. Residential zip codes were used to quantify the number and distance of the closest identified patient-centered medical homes (PCMH) to each participant's residential zip code. Chart review consisted of access to a participant's electronic medical record and was limited to collection of data in the informed consent.

Subjects

The target sample size was 100 participants between ages 18 to 89 years old, with repaired or unrepaired CHD who require at least annual follow up at the southeastern regional comprehensive ACHD care center. The target population consists of individuals with chronic health conditions and was the rationale for including patients who require ACHD follow-up at least annually. Additionally, subjects were recruited only if they were able to speak and read English and voluntarily provide consent. Subjects with known developmental delay, pregnant

teenagers or adults requiring less than annual CHD follow up were excluded. No participants were employees or subordinates of anyone on the project team.

Instruments

The study included a Barriers to Care Questionnaire (BCQ) which is a 39-item scale originally developed to assess barriers to care for children with special needs (Seid, Sobo, Gelhard & Varni, 2004). The questionnaire was designed to measure barriers to accessing care or adhering to medical advice. The BCQ has been validated to assess barriers to care and has been shown to be feasible, reliable and valid for those with special healthcare needs (Seid, Opipari-Arrigan, Gelhard, Varni & Driscoll, 2009).

The BCQ yields a 0-100 score with higher scores denoting fewer barriers to care. A five-point Likert scale was used to rate the extent to which each item is perceived as a barrier to care where: 1=Almost always (0 points), 2=often (25 points), 3=sometimes (50 points), 4=occasionally (75 points) and 5=almost never (100 points). Points were totaled and then divided by the total number of points possible (3900). This yielded BCQ scores of 0-100 with higher scores representing fewer barriers to care. The BCQ subscales include pragmatics, skills, expectations, marginalization and knowledge & beliefs (appendix A). Pragmatic barriers cover logistics and cost concerns that may interfere with access to care. Skills are learned strategies to navigate effectively within the healthcare system (Sobo, & Seid, 2003). Expectations are barriers in the form of anticipating receipt of poor-quality care (Seid, Opipari-Arrigan, Gelhard, Varni & Driscoll, 2009). Marginalization is the internalization of negative healthcare experiences that may represent a barrier to care (Seid, Opipari-Arrigan, Gelhard, Varni & Driscoll, 2009). The knowledge & beliefs subscale quantifies barriers where ideas about the nature and treatment of disease may differ from mainstream medicine (Seid, Opipari-Arrigan, Gelhard, Varni & Driscoll, 2009).

The project sought to determine if individuals were aware of the Agency for Healthcare Research and Quality (AHRQ) definition of a patient-centered medical home. Additional data captured included patterns of recent healthcare utilization, timeframe in which participants were last seen by any healthcare provider, setting seen (hospital/ER, urgent care, primary care provider office, pediatric cardiologist, non-congenital cardiologist office or other) and the reason prompting that visit (routine care, new symptom, recommendation of another provider or other). There were 17 Likert scale questions designed to assess perception of healthcare needs and 5 additional Likert scale questions specifically related to primary care utilization for patients who identified as having seen a primary care provider within the past year. Reliability of this portion of the questionnaire is addressed in the data analysis. A lack of evidence about the use of this tool in adults with congenital heart disease warrants a reliability analysis.

Data Collection

Data were collected and participant confidentiality protected using REDCap online. REDCap is a secure, web-based application designed to support data capture for research studies, providing an interface for validated data entry; audit trails for tracking data manipulation and export procedures; automated export procedures for seamless data downloads to statistical software; and procedures for importing data from external sources (Harris, Taylor, Thielke, Payne, Gonzalez & Conde, 2009). To gain access to REDCap, institutions are required to have an agreement with Vanderbilt University (Partridge & Bardyn, 2018). After reviewing REDCap study design modules, survey questions were entered into REDCap database during the design phase and were moved to production mode following a brief testing phase by project team members. Data collected via REDCap online is stored locally on the university's REDCap database. Use of REDCap online streamlined the data collection process through the use of branching logic questions. A codebook was automatically generated and data directly imported

into statistical software which reduced time spent on data cleaning (Harris, Taylor, Thielke, Payne, Gonzalez & Conde, 2009).

No data were loaded into the tablets or personal electronic devices utilized to access the survey. The REDCap database is a password-protected research tool which is Secure Socket Layer (SSL) encrypted, firewall protected, and Health Insurance Portability and Accountability (HIPPA) compliant (REDCap, 2018). REDCap is managed by the university affiliated with the project site. The application is linked to user ID which allows for audit trails of data access. Data continues to be stored in REDCap database for future research as obtained in the informed consent document. The data can be accessed on campus or through the university's Virtual Private Network (VPN) only by the investigators. No hard copies of personal information exist.

Results

A convenience sample of 30 adults with congenital heart disease presenting for an outpatient congenital cardiac clinic visit were successfully recruited for this DNP Project. Thirty-four participants were approached, 4 declined leaving the total number recruited at 30. Statistical consultation was provided by faculty with expertise in statistical analysis and research. Raw data from REDCap was imported into Statistical Package for Social Sciences (SPSS) version 23.0. Descriptive statistics characterized the sample's demographics, access to care, responses to the BCQ and patient perception components. These include frequency distribution for continuous variables expressed as means (with SD) or medians (with ranges). Table 1 summarizes the participant characteristics.

Table 1: *Sample Demographic Features, Access to Care and BCQ Scores*

Variable	N(%)	BCQ Score, Mean ± SD
Race:		
White/Caucasian	25 (83.3)	78±26
Black/African American	3 (10)	75±22
Asian/Pacific Islander[a]	1 (3.3)	-
Other[b]	1 (3.3)	-
Gender Identity		
Male	17 (56.7)	82±15
Female	13 (43.3)	73±32
Highest Education		
Some high school	2 (6.7)	49±69
High School degree or GED	7 (23.3)	72±31
Associates degree	5 (16.7)	82±15
Trade/Technical school	4 (13.3)	87±10
Bachelor's degree	7 (23.3)	78±18
Graduate degree	3 (10)	91±3
Other	2 (6.7)	88±12
CHD Severity		
Marelli Group 1	13 (43.3)	79±16
Marelli Group 2	17 (56.7)	78±29
Insured		
Commercial Insurance (including ACA)	20 (67)	77±21
Medicaid	2 (7)	94±1
Medicare	11 (37)	74±36
Military/Tricare/VA[c]	1	*
Self-pay / Un-insured[d]	1	*
Other[e]	1	*
Have PCP (seen in past year)		
No	8 (27)	71±33
Yes	22 (73)	81±22

Notes. [a,b,c,d,e] BCQ score constant and thus omitted

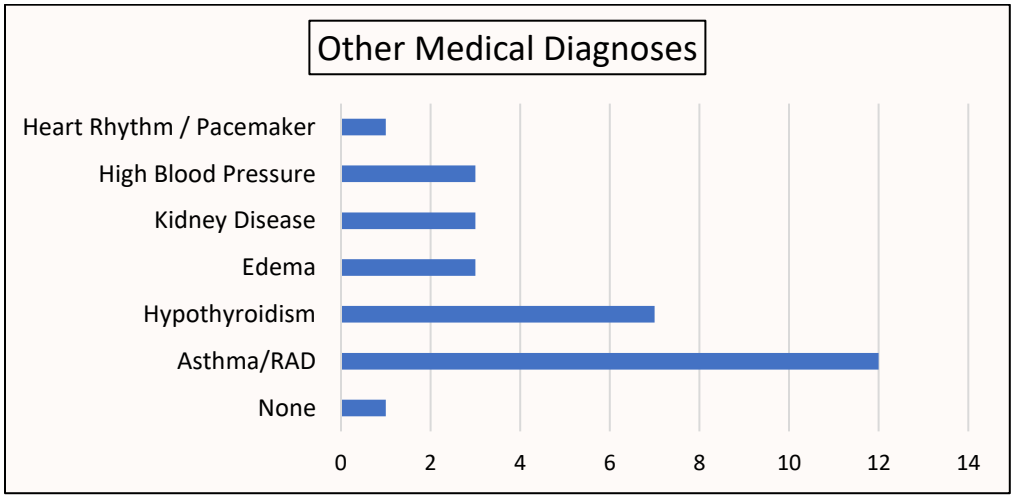
Utilizing the participant's congenital diagnosis each participant was classified into two groups of CHD severity as defined by modified Marelli criteria (Table 1). Participants with

CHD belonging to Group 1 are those most likely to have been associated with cyanosis or requiring surgery early in life. Group 2 included all remaining lesions (Marelli, Mackie, Ionescu-Ittu, Rahme & Pilote, 2006).

Of the 34 eligible participants who were approached, 30 (88%) enrolled and 4 (12%) declined. At the time of the study, mean age was 44 (SD = 16.9 years); 57% (n=17) male; 43% (n=13) had severe CHD defined as modified Marelli group 1; 3% (n=1) was uninsured; 80% (n=24) had never heard of a PCMH.

After reading the AHRQ definition of a PCMH 43% (n=13) indicated they would be very likely to utilize one for care; 33% (n=10) indicated they would be somewhat likely to utilize a PCMH for care. 77% (n=23) would be willing to drive 1-50 miles to obtain care at a PCMH; 13% (n=4) would be willing to travel 51-100 miles for care at a PCMH. General health was described as: 3% (n=1) excellent; 30% (n=9) very good; 30% (n=9) good; 33% (n=10) fair; 3% (n=1) poor. The presence of additional medical diagnoses underscores population complexity and need for additional medical support as summarized in (table 2).

Table 2: Other Medical Diagnoses



BCQ scores ranged from 0-100. Among this sample, the mean was 78.42, (SD=24.14). Internal consistency and reliability of the BCQ was assessed using Cronbach's alpha. An α coefficient > 0.7 indicates sufficient internal consistency for comparing groups and an α coefficient of >0.9 is preferred when comparing individuals (Kim & Mallory, 2017). Internal consistency using the BCQ total score was strong, with an α of 0.98.

The relationship between health insurance coverage on BCQ scores was investigated using Spearman's rho. Among those with commercial insurance, there was no correlation between variables, r= -0.266, n=30, p=0.156. Among those with Medicare, there was no correlation between variables, r= 0.092, n=30, p=0.629. Among those with military/VA coverage, there was no correlation between variables, r= -0.054, n=30, p=0.778. Among those with Medicaid, there was no correlation between variables, r= 0.232, n=30, p=0.218. Among those who were self-pay/uninsured, there was no correlation between variables, r= 0.118, n=30, p=0.534. Among those who marked other, there was no correlation between variables, r= 0.247, n=30, p=0.188. The relationship between seeing a PCP within the past year, on BCQ scores was also investigated using Spearman's rho. Among those having seen a primary care provider in the past year, there was no correlation between variables, r= 0.169, n=29, p=0.382. The findings are summarized in (Table 3).

Table 3: *Correlation of Independent Variables to BCQ Scores*

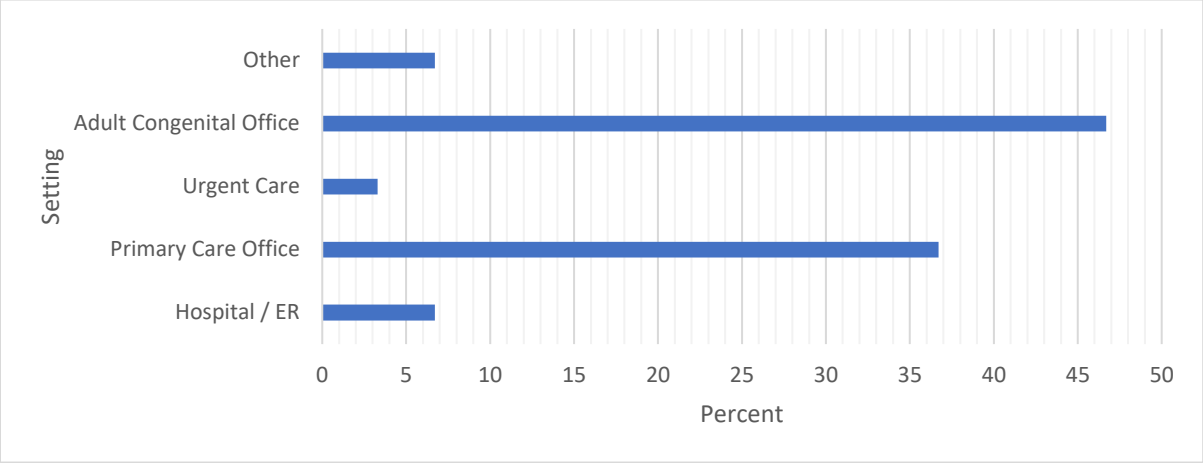
Variable	*N*	*r*	r^2	*p-value*
Commercial Insurance	30	-0.266	0.071	0.156
Medicare	30	0.092	0.008	0.629
Military/VA insurance	30	-0.054	0.003	0.778
Medicaid	30	0.232	0.054	0.218
Self-pay / Un-insured	30	0.118	0.014	0.534
Other Insurance	30	0.247	0.061	0.188
Primary Care Provider	29	0.169	0.029	0.382

Independent samples t-tests were conducted to compare the mean BCQ scores for health insurance coverage. There was no significant difference in BCQ scores for participants who were commercially insured (M=77.37, SD=21.42), and those not commercially insured (M=80.51, SD 30.03; $t(28)= -0.331$, $p = 0.74$, two tailed). There was no significant difference in BCQ scores for participants who had Medicaid (M=93.59, SD=0.91), and those who did not (M=77.33, SD=24.65; $t(28)= 0.917$, $p = 0.367$, two tailed). There was no significant difference in BCQ scores for participants with Medicare (M=73.60, SD=35.82) and those without (M=81.21, SD=14.29; $t(11.8)= -0.674$, $p = 0.513$, two tailed).

Independent samples t-tests could not be run for those with military/VA, self-pay/uninsured, or other as each category only had an N of 1 which would violate assumptions for running the tests. While an observable difference in the mean BCQ scores was observed in some groups, analysis did not result in statistical significance. These findings should be interpreted with caution as several factors such as sample size, study design and participant characteristics may have impacted the data.

When looking at patterns of healthcare utilization, 73% (n=22) indicated having a primary care provider (PCP) they had seen in the past year; 7% (n=2) had a PCP but had not seen them in over a year; 20% (n=6) indicated no or other. 70% (n=21) presented for routine care; 17% (n=5) sought care for a new symptom; and 13% (n=4) had other reasons for seeking care. The location participants last sought medical care is summarized in table 4.

Table 4: Setting of Last Medical Care



Analysis of the 17 questions relating to participant perceptions yielded the following descriptives (Table 4). Of the 30 participants, 29 (97%) completed all the questions and 1 (3%) did not. Internal consistency and reliability for these questions was measured using Cronbach's alpha. An alpha coefficient of 0.7 demonstrates sufficient internal consistency and reliability for group comparisons (Kim & Mallory, 2017). Cronbach's alpha for these questions was 0.85 which demonstrates strong internal consistency and reliability.

Table 5*: Participant Responses to Perception Questions*

Item	Strongly Agree *N* (%)	Agree *N* (%)	Neutral *N* (%)	Disagree N(%)	Strongly Disagree N(%)
I am more aware when I need to seek medical care	22 (73)	6 (20)	1 (3)	-	1 (3)
I am more afraid to seek medical care (findings)	4 (13)	4 (13)	7 (23)	6 (20)	9 (30)
I am afraid of medical procedures	2 (7)	6 (20)	8 (27)	7 (23)	7 (23)
I am likely to have other medical problems	4 (13)	12 (40)	7 (23)	2 (7)	5 (17)
I am no different and do not require specialized care	1 (3)	1 (3)	2 (7)	8 (28)	17 (59)
I worry about my future	11 (37)	7 (23)	6 (20)	4 (13)	2 (7)

I spend too much time dealing with my health already	4 (13)	5 (17)	10 (33)	8 (27)	3 (10)
I take medications that cause bad side effects	3 (10)	3 (10)	8 (27)	6 (20)	10 (33)
I do not trust providers not trained in my heart defect	9 (30)	4 (13)	4 (13)	4 (13)	9 (30)
My CHD doctor would tell me if I needed to see someone else	16 (53)	12 (40)	-	-	2 (7)
I do not have time to see another physician	1 (3)	4 (13)	4 (13)	9 (30)	12 (40)
I do not have healthcare coverage	2 (7)	1 (3)	1 (3)	5 (17)	21 (70)
I'm afraid another physician won't communicate with my CHD provider	3 (10)	9 (30)	5 (17)	8 (27)	5 (17)
My CHD doctor can manage all of my medical needs	5 (17)	7 (24)	13 (45)	3 (10)	1 (3)
I cannot do the physical activities I want to do	9 (30)	7 (23)	6 (20)	6 (20)	2 (7)
I feel guilty about the stress CHD has on my family	7 (23)	9 (30)	8 (27)	2 (7)	4 (13)
My condition is likely to get worse	7 (23)	11 (37)	7 (23)	2 (7)	3 (10)

Analysis of the 22 participants who indicated they had seen a PCP in the past year yielded the following results (table 5). Internal consistency and reliability for these questions was measured using Cronbach's alpha. An alpha coefficient of 0.7 demonstrates sufficient internal consistency and reliability for group comparisons (Kim & Mallory, 2017). Cronbach's alpha for these questions was 0.16 which did not demonstrate internal consistency and reliability.

Table 5: Perceived Primary Care Needs

Item	Strongly Agree *N* (%)	Agree *N* (%)	Neutral *N* (%)	Disagree N(%)	Strongly Disagree N(%)
I only see a doctor when I am sick	4 (18)	2 (9)	3 (14)	9 (41)	4 (18)
My PCP is not comfortable with my CHD	2 (9)	4 (18)	5 (23)	6 (27)	5 (23)
I always let my CHD doctor know if my PCP has prescribed a new med or treatment	10 (46)	10 (46)	2 (9)	-	-
I trust that my PCP communicates well with my CHD cardiologist	7 (32)	5 (23)	7 (32)	2 (9)	1 (5)
My PCP is able to provide most of my healthcare needs	5 (23)	10 (46)	5 (23)	1 (5)	1 (5)

Discussion

It was hypothesized that BCQ scores would be worse (lower) for participants without health insurance, without a primary care provider and for those who experienced gaps in care. However, analysis revealed no statistically significant difference in scores among these groups. This is in contrast to findings that barriers to care were significantly associated with experiences to primary care for vulnerable children with asthma (Seid, 2008). The lack of association between insurance status and BCQ scores may be explained by the fact that all subjects were recruited from a clinic which provides care regardless of insurance status. Those who are self-pay or are un-insured may apply for charity care from the organization.

Additionally, small sample size and the inclusion of only one uninsured participant may contribute to the findings. There may have been participant confusion on insurance status as several participants answered in agreement that they do *not* have health insurance in response to a question on the patient perceptions. Receiving organization charity care may be viewed as a

type of healthcare coverage. Simplification of insurance status may help clarify responses. According to demographic responses, a majority of participants were insured, had seen a PCP in the past year, were Caucasian and possessed education beyond high school. Utilizing a matched group of uninsured participants as well as those who experience gaps in care warrants further investigation.

Additionally, the population that would benefit most from a PCMH included a high proportion of Medicaid users and a majority with intellectual disability according to Berens and Peacock (2015). This study had a relatively low number of participants on Medicaid and excluded those with developmental disability. The study sought to enroll a larger number of participants. Plans to have a dedicated space for participants were not realized. This interfered with ability to find a private quiet environment to explain the study and impacted the enrollment and completion of surveys while in clinic.

Of participants who have seen primary care in the past year, a majority strongly agreed they were more aware of when they needed to seek care. Additional common findings were awareness of likelihood of having other medical problems and concerns about the future. This project demonstrated the existence of multiple non-cardiac diagnoses in this population which Lauffenberger et al. (2017) indicate would benefit from a PCMH. However, despite these findings, participants frequently rely on their ACHD provider to tell them if they need to see someone else and nearly a quarter of participants believe their ACHD provider can manage all of their healthcare needs. This was an expected finding according to Kirkpatrick, Kim and Kaufman (2012) and Ellison et al. (2013) who describe challenges facing ACHD clinicians and the need for additional services to provide optimal care.

Ethnic diversity affects access to healthcare and the homogeneity of participants enrolled in this project may reflect continued struggles for healthcare equality in this region.

Additionally, due to financial and time constraints this project was limited to participants able to read English. Language has been shown to be a significant barrier to healthcare access and exclusion of non-English speakers may have impacted this project's findings.

Even though data on the timeframe and location of last primary care visits were captured, more specific questions regarding issues caused by lack or change in insurance leading to gaps in care were not asked. The presence of additional non-cardiac diagnoses found in this project are consistent with findings from Seckler et al. (2015), seen as this population ages. However, this study contributes to the literature by demonstrating a lack of knowledge about PCMHs in a population where the presence of additional medical diagnoses underscores their complexity and need for additional medical support.

Practice Implications

Lack of awareness on PCMH was a significant finding in this project. Education on the how PCMHs improve healthcare outcomes for those with chronic health conditions (Mosquera et al., 2014), is an important first step toward improving health outcomes for those with ACHD. Because most participants rely on their ACHD provider to inform them if they need to see someone else, referrals to and assistance locating a PCMH may be beneficial. However, it is important to acknowledge challenges surrounding this population. Many expressed distrust for providers without expertise in their particular heart condition; some believe that their ACHD provider can manage all of their medical needs. Given the importance of primary care, this project has implications for practitioners and organizations. At the organizational level, data should be collected and analyzed according to race & ethnicity to assure that change in healthcare coverage does not lead to inequality of care. At the interpersonal level, the author suggests improvements in patient education and empowerment. Providers should anticipate how

to address multiple barriers to care, beyond the limited focus of insurance status. Ease of inter-provider communication may be a factor in establishing a medical neighborhood where patients are more comfortable receiving primary care.

Limitations

It was hypothesized that BCQ scores would be worse (lower) for participants without health insurance and without a primary care provider. However, analysis revealed no statistically significant difference in scores among these groups. This may be explained partially by the small sample size and by the inclusion of only one uninsured participant. The sample was homogenous with a majority of participants who were insured, had seen a PCP in the past year, were Caucasian and possessed education higher than a high school education. Ethnic diversity affects access to healthcare and limitations as suggested by this project may reflect continued struggles. Enrolling a more ethnically diverse group of matched uninsured participants as well as those who have experienced gaps in care warrants further investigation. Additionally, due to financial and time constraints this project was limited to participants able to read English. Language has been shown to be a significant barrier to healthcare access and exclusion of non-English speakers may have impacted this project's findings.

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APPENDIX A – MATRIX TABLE

Lauffenburger, J. C., Shrank, W. H., Bitton, A., Franklin, J. M., Glynn, R. J., Krumme, A. A., ... Choudhry, N. K. (2017, January 17). Association between patient centered medical homes and adherence to chronic disease medications: A cohort study. *Annals of Internal Medicine*, *166*, 81-88. http://dx.doi.org/10.7326/M15-2659				**II**
Hypothesis/Questions	**Design**	**Sample**	**Measurement**	**Results/Implications**
To evaluate the effectiveness of medication compliance for 1 of 3 conditions for pts initiating a new medication therapy in a PCMH	Retrospective cohort study using claims data from Aetna	Adult Pts (18 and older) initiating therapy with oral hypoglycemic, antihypertensive or cholesterol lowering medication between 1/1/11 and 12/31/2013	NPPES database identified 53,771 practices with≥1 study pt. Linked to NCQA file identifying 3,533 medical homes and 50,238 control practices. There was good agreement between data sets	Receipt of care in a PCMH is associated with better adherence among pts initiating treatment with medications for common chronic diseases
Mosquera, R., Avritscher, E., Samuels, C., Harris, T., Pedroza, C., Evans, P., ... Tyson, J. (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 the American Medical Association*, *312*, 2640-2648. http://dx.doi.org/10.1001/jama.2014.16419				**II**

Hypothesis/Questions	Design	Sample	Measurement	Results/Implications
Did high risk children with chronic illness benefit from a PCMH AEB preventing serious illness, hospital stay > 7 days or /& reduce cost compared to those getting usual care	Randomized clinical trial	Children age 81 or younger with a chronic illness living w/in 1 hour of UTH and high health care use. Enrolled b/t 3/11 and 2/13 with evaluations continuing through 8/31/13	Telephone calls and questionnaires were used at the medical homes; pts with usual care were initially called but this was abandoned d/t oupt visits not reliably identified by parents. However, alternative use of Medicaid billings was utilized to compare the two treatment groups and parental ratings of outpt care by personnel univolved in care	A PCMH was shown to reduce serious illness and cost in high risk children with chronic medical conditions
Kirkpatrick, J. N., Kim, Y. Y., & Kaufman, B. D. (2012). Ethics priorities in adult congenital heart disease. *Progress in Cardiovascular Diseases, 55*, 266-273. http://dx.doi.org/10.1016/j.pcad.2012.10.004				**VII**

Hypothesis/Questions	Design	Sample	Measurement	Results/Implications
Ethics of clinical care of ACHD patients, ethics research and clinical policy w/ regard to caring for challenging ACHD pts, improving transition from pediatric to adult CHD care, advanced planning and costs	Qualitative descriptive analysis	n/a	Review of proposed measurements in priorities sections under each heading was appropriate (ACHD clinicians should have access to supportive services such as social work, psychiatrist, ethicist, Advocacy groups such as ACHA	ACHD patients comprise a clinical, social and ethical challenges. ACHD clinicians are needed and focus on professionalism, end of life care and cost-conscious medicine are imperative. Pairing with ethicist, psychologist, palliative care and chaplains are recommended to provide optimal care

Ellison, S., Lamb, J., Haines, A., O'Dell, S., Thomas, G., Sethi, S., ... Mahadevan, V. S. (2013). A guide for identification and continuing care of adult congenital heart disease patients in primary care. *International Journal of Cardiology*, *163*, 260-265. http://dx.doi.org/10.1016.j.ijcard.2011.06.020				**VI**
Hypothesis/Questions	**Design**	**Sample**	**Measurement**	**Results/Implications**
Will the use of a toolkit (ACHD care algorithm) improve ACHD outcomes in primary care	Qualitative descriptive analysis utilizing a retrospective review of diagnosis codes. Test	In a practice of 6500 pts: 27 ACHD pts were identified (3 complex, 4 moderately complex and 20 simple)	The study relied on diagnosis codes for CHD in the UK. Specific measures were unclear	There is wide disparity b/t optimal and current care of ACHD pts. By identifying ACHD pts in primary care the toolkit could help improve quality,

	was a pilot – feasibility study in 2010			timeliness of care, pt experience and wellbeing
Berens, J. C., & Peacock, C. (2015). Implementation of an academic adult primary care clinic for adolescents and young adults with complex, chronic childhood conditions. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach*, *8*, 3-12. http://dx.doi.org/10.3233/PRM-150313				**VII**
Hypothesis/Questions	**Design**	**Sample**	**Measurement**	**Results/Implications**
Describes the development and implementation of the Transition Medicine Clinic (TMC)	Qualitative descriptive analysis	332 patients establishing care in the TMC between 2005 to July 2011	Retrospective analysis of resource utilization	Population faces unique challenges (w/c use, Down's syndrome, > 80% Medicaid, 65% intellectual disability). A CCC requires medical providers and support staff that is equipped to familiar with issues and willing to spend considerable time and effort outside of routine OV in health care coordination.
Gurvitz, M., Valente, A. M., Broberg, C., Cook, S., Stout, K., Kay, J., ... Landzberg, M. (2013). Prevalence and predictors of gaps in care among adult congenital heart disease patients. *Journal of the American College of Cardiology*, *61*, 0735-1097. http://dx.doi.org/10.1016/j.jacc.2013.02.048				**VI**

Hypothesis/Questions	**Design**	**Sample**	**Measurement**	**Results/Implications**
To quantify the prevalence in gaps in cardiac care, identify gap predictors, and assess barriers to care among ACHD pts	Multicenter-prospective cross section study	922 subjects age ≥18 presenting for a NPV at one of 12 ACHD centers in the US	Questionaire given to new pts at first vist (interview); continuous and categorical variables were analyzed appropriately.	ACHD pts have gaps in cardiac care at ~ 19 y/o when transistion is contemplated. More common w/mild-mod diagnosis and at particular locations
Gurvitz, M., Marelli, A., Mangione-Smith, R., & Jenkins, K. (2013). Building quality indicators to improve care for adults with congenital heart disease. *Journal of the American College of Cardiology, 62*, 735-1097. http://dx.doi.org/10.1016/j.jacc2013.07.099				**VII**
Hypothesis/Questions	**Design**	**Sample**	**Measurement**	**Results/Implications**
To develop QI assessment tools for outpt management of 6 ACHD pt conditions to improve quality of care	Working groups of ACHD experts reviewed published data and guidelines from US, Canada and EU to identify potential quality indicators	n/a;	Rand/UCLA Delphi panel methodology to arrive at final set of QIs	8 quality indicators for ASDs; 9 for aortic coarctation; 12 for Eisenmenger; 9 for Fontan; 9 for d-TGA and 8 for TOF
Seckeler, M., Moe, T., Thomas, I., Meziab, O., Andrews, J., Heller, E., & Klewer, S. (2015). Hospital resource utilization for common noncardiac diagnosese in adult survivors of single cardiac ventricle.				**III**

American Journal of Cardiology, 116, 1756-1761. http://dx.doi.org/10.1016/jamjcard.2015.09.008				
Hypothesis/Questions	**Design**	**Sample**	**Measurement**	**Results/Implications**
To review HCRU for pts with SV hospitalized for non-cardiac reasons	Retrospective database review of hospital discharges (120 academic centers and 308 affiliated community hosps in US) from Jan 2011 to Nov 2014	**Group 1** -nonCHD: 2,083,651 -SV CHD: 590 subj **Group 2** -nonCHD 2,131,046 -SV CHD: 297	Research variables were clearly conceptualized; accuracy of instruments to detect dx of single ventricle was sensitive 80-85% of time.	Pts w/ SV were id'd using ICD-9 codes and stratified into 2 age groups (18-29 & 30-40); evaluated LOS, direct costs, ICU admission; mortality rates; finding stress importance of good PC in this population
Lu, Y., Agrawal, G., Lin, C., & Williams, R. G. (2014). Inpatient admissions and costs of congenital heart disease from adolescence to young adulthood. *American Heart Journal*, *168*, 948-955. http://dx.doi.org/10.1016/j.ahj.2014.08.006				**IV**

Hypothesis/Questions	Design	Sample	Measurement	Results/Implications
What are the healthcare resource utilization patterns and cost associated with CHD care in young adults?	Descriptive Retrospective study on inpt admissions of CHD patients	California inpt admissions of CHD patients age 10-29 y/o between 2005 and 2009. Pregnancy r/t admissions excluded	3 CA databases of inpt admissions; the Healthcare Cost and Utilization Project (HCUP); and CA Hospital Annual Utilization Data (2005-2009);	Young adults use fewer resources d/t natural hx of CHD resulting in fewer surgeries in that time but more frequent (less costly) medical admissions (mostly arrhythmia and HF)
Khairy, P., Ionescu-Ittu, R., Mackie, A., Abrahamowicz, M., Pilote, L., & Marelli, A. (2010). Changing mortality in congenital heart disease. *Journal of the American College of Cardiology, 56,* 1149-1157. http://dx.doi.org/10.1016/j.jacc.2010.03.085				**II**
Hypothesis/Questions	**Design**	**Sample**	**Measurement**	**Results/Implications**
Characterize the trends in mortality in pts with CHD	Descriptive retrospective cohort study	An open population based cohort study of patients in Quebec, Canada from July 1987 to June 2005.	ICD-9 codes; mortality data were collected (including name, demographics and Medicare number); statistical analysis and rationale were explained	A total of 8,561 deaths occurred in 71, 686 pts with CHD followed for 982, 363 pt years with a shift away from infant deaths towards adults with steady increase in age at death.