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The School Age Child with Congenital Heart Disease

CE **2.5 ANCC Contact Hours**

Abstract

Currently, in the United States, there are approximately 1 in 150 adults living with congenital heart disease (CHD) (Go et al., 2014). Infant and childhood mortality related to CHD decreased by 31% between 1987 and 2005 (Khairy et al., 2010). This survival trend is predicted to increase each year due to advancements in treatment and management of CHD. This significant shift in the epidemiology of CHD requires nurses to take action in preparing children with CHD and their families for their teenage years and young adulthood. The school-age child is the ideal age to begin teaching the child about their healthcare needs and how to care for themselves in preparation for the future. The school-age child with CHD has specific physical, intellectual, emotional, and developmental needs that must be considered and managed using a multidisciplinary approach. Pediatric nurses must be aware of these needs as they help the child and their family seamlessly and successfully transition into young adulthood as a happy and healthy CHD survivor.

Key words: Chronic illness in children; Congenital heart disease; Health-related quality of life; Pediatric nursing.

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Congenital heart disease (CHD) is the most common birth defect, occurring in approximately 8 out of every 1,000 births (Go et al., 2014). The American Heart Association (AHA) estimates that 1 in 150 adults are living with CHD (Go et al., 2014). Most of these children are diagnosed in early childhood and infancy (AHA, 2013). Recent recommendations for critical CHD screening with pulse oximetry added to universal newborn screening during the first 24 hours of life have been shown to identify the presence of CHD prior to hospital discharge (Centers for Disease Control and Prevention, 2013). It is estimated that 25% of infants with CHD will require invasive treatment during the first year of life (Go et al., 2014).

Congenital heart disease is classified according to patterns of blood flow and will vary from simple to complex (Table 1). It may occur in conjunction with or as a complication of specific genetic conditions (Table 2). Identification of both CHD and genetic conditions in the newborn period will help to educate and prepare families for the challenges their child may face (Pierpont et al., 2007). Chromosomal anomalies alter the life experiences of children with CHD. In one study, parent report of the health-related quality of life (HRQOL) of 4-year-old children with CHD and chromosomal anomalies was lower than that of children with CHD without chromosomal anomalies, when matched for CHD and surgical repair (Garcia Guerra et al., 2014).

Children with many types of CHD are living beyond the expectations of the healthcare providers who performed their initial repair and beyond the expectations of the healthcare team who cared for them in the very early stages of their disease process (Reid et al., 2006). Advances in cardiac surgery, cardiac catheterization, interventional cardiology, noninvasive imaging, early diagnosis with fetal assessment, and complex critical nursing care have led to 85% to 90% of children with CHD reaching adulthood (Moons, Bovijn, Budts, Belmans, & Gewillig, 2010; Webb & Williams, 2001). Unfortunately, some families do not appreciate the need for long-term follow-up and care, believing instead that their child's repair or stable cardiovascular status deems the visits unnecessary (Gurvitz et al., 2013). This article focuses on needs of the school-age child (ages 6–12 years) (Rodgers, 2010) with CHD. Promotion of health in school-age children involves chronic disease management, health maintenance education, and anticipatory guidance to prevent future health problems. Including the child early in healthcare and education about their chronic condition will improve self-care and accountability for their health in the future (Mickley, Burkhart, & Sigler, 2013).

Health Maintenance in Children With CHD

Despite the complexities of CHD, children with CHD have the same needs as other children within the realm of routine issues, such as neurodevelopment, healthy weight management, dental care, and immunizations. As the school-age child's world continues to expand, a highly significant relationship with the school and community emerges. Parents are no longer the single, absolute authority they once were in the child's life. This can be a very difficult time for not only the child, but also the parent. Worry and fear often dominate the mind of a parent of a chronically ill child (Duncan & Caughy, 2009; Lee & Rempel, 2011). Parental anxiety and apprehension can dramatically affect the parenting skills and discipline style (Duncan & Caughy, 2009; Lee & Rempel, 2011).

Nurses caring for children with CHD are uniquely skilled at educating families about the importance of health maintenance needs. Nurses must partner with parents in order to develop an individualized health maintenance and promotion plan that will address the child's physical, developmental, psychosocial, and cognitive needs as well as foster parental well-being and appropriate coping mechanisms.

Neurodevelopment

Children with CHD often experience neurodevelopmental complications such as learning disabilities, visual motor integration, and motor delays (Marino et al., 2012; Wernovsky, 2006). Marino et al. (2012) found that only a minority of children with particularly complex heart defects are considered to be developmentally age appropriate. Incidence of learning disabilities, behavior issues, speech, and/or motor delays varies greatly among this population.

It has been noted in several different research cohorts that the severity of CHD is a significant predictor of the child's neurodevelopmental outcome (Wernovsky, 2006). Children with milder forms of CHD, such as atrial or ventricular septal defects, are found to have a lower incidence of neurodevelopmental disabilities, whereas more complex defects (e.g., hypoplastic left heart syndrome) are associated with higher incidence of children with developmental deficits (Marino et al., 2012; Wernovsky, 2006). This increased risk may be related to hypoxemia or subtle brain injury from cardiovascular compromise (Batra, Alexander, & Silka, 2012).

Table 1: Classification of CHD

Acyanotic With Increased Pulmonary Blood Flow	Acyanotic With Obstruction of Systemic Blood Flow
Atrial septal defect (ASD) Ventricular septal defect (VSD) Patent ductus arteriosus (PDA) Complete atrioventricular canal (CAVC)	Coarctation of the aorta Interrupted aortic arch (IAA) Aortic stenosis (AS)
Cyanotic-Obstruction of Pulmonary Blood Flow	**Cyanotic-Variable Pulmonary Blood Flow**
Pulmonary stenosis (PS) Pulmonary atresia (PA) Tetralogy of fallot (TOF)	Hypoplastic left heart syndrome (HLHS) Truncus arteriosus (TA) Transposition of the great arteries (TGA) Total anomalous pulmonary venous return (TAPVR)

Attention deficit neurodevelopmental disorders are common in the school-age child with CHD and can be a further negative factor contributing to academic struggles (Shillingford et al., 2008). Adverse cardiovascular events with stimulant medications typically used to treat attention deficit hyperactive disorders (ADHD) have been contested by recent studies showing no increased risk with these drugs (Cooper et al., 2011; Schelleman et al., 2011). School-age children with CHD may be treated safely with stimulant medications for ADHD (Cooper et al., 2011; Marino et al., 2012; Schelleman et al., 2011). Recent recommendations support consultation with the child's cardiologist before beginning ADHD medications (Batra et al., 2012). Routine electrocardiogram evaluation remains controversial. The nurse in the school setting is a valuable resource for elementary school educators because they are able to share current research regarding how the neurodevelopmental expectations of children with CHD vary among the defects as well as the individual child. The school nurse is also well positioned to facilitate the discussion of neurodevelopmental evaluation in a child with CHD who has not been closely monitored or has been lost to medical follow-up.

Many school-age children with CHD require additional academic provisions and special education services. An individualized education plan (IEP) is required for any child receiving special education services for learning disabilities, inattention, hyperactivity, or behavioral concerns (O'Brien, Evangelista, Green, & Uzark, 2012; Wernovsky, 2006). As a component of the Individuals with Disability Education Improvement Act (IDEA) an IEP is a formal educational plan with measurable goals for the academic year. With or without an IEP, children with CHD may qualify for services under Section 504 of IDEA that requires that children with disabilities have equal access to education. This includes matters of medical emergencies, accommodations for physical or behavioral limitation, and other modifications required to allow for reasonable participation. The school nurse may help in the creation of an IEP for the child with CHD (O'Brien et al., 2012) providing a knowledgeable and consistent source of support in the school setting.

Medical follow-up for children with CHD may hinder the child's attendance in school and participation in school activities. School absence is a lingering issue for children with CHD (O'Brien et al., 2012). They often miss several days per year related to frequent, routine appointments, and repeated testing. This becomes more of an issue if they do not live near their specialized pediatric cardiac center, as travel is a required part of their care. School nurses are in a good position to observe the child's behavior and school performance related to education, medication compliance, and effects of medications and diet on behavioral issues specific to the child in the classroom. Their observations, assessments, and knowledge of effective interventions for the school-age child with CHD are essential in developing a long-term plan for the child in the school setting. Nurses who coordinate care for patients, advanced practice nurses, nurse case managers, and nurse navigators may help with clustering appointments, testing, and treatments, in order to help decrease travel time, school days missed, and the overall cost to the family.

Healthy Weight Management

In the United States, approximately one fourth of 2 to 5 year olds, one third of school-age children, and one third of adolescents are classified as overweight or obese (Ogden, Carroll, Kit, & Flegal, 2014). Pinto et al. (2007) estimate that over 25% of children with heart disease are obese or overweight. Congential heart disease often carries assumed physical limitations; therefore, children with CHD are at higher risk of becoming overweight or obese when compared to children without CHD. The nutritional state and physical development of children with CHD must be followed closely. Regular monitoring and plotting the child's height and weight on growth charts is essential in establishing the child's individual norm as well as patterns in their physical growth and development across the time continuum (Woodward, 2011). Growth charts provide nurses, patients, and families with a visual depiction of how the

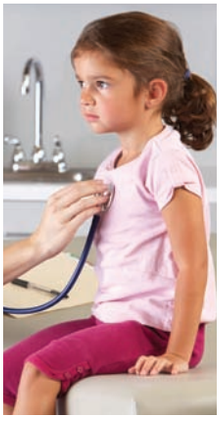
child is progressing on their own growth curve. This can be a very helpful tool when teaching children about healthy habits and their relation to growth and development. It is important to note that many cardiac medications are prescribed according to weight and need to be adjusted in light of weight loss or gain (Woodward, 2011). Nurses must provide this education to patients and their families if medication levels are to remain therapeutic.

In 2013, AHA published guidelines for promotion of physical activity in children and adults with CHD (Longmuir et al., 2013). Regular exercise can assist the child with CHD in maintaining a healthy weight, foster normal physical development, boost self-esteem, and help with acceptance on sports teams, and as such, acceptance into peer groups (Longmuir et al., 2013). Children with CHD should be strongly encouraged to exercise and maintain a healthy weight, but the complexity of their cardiac limitations must be taken into consideration. Exercise, whether mild, moderate, or strenuous, produces an increase in cardiac output. This increase in cardiac output produces an increase in pulmonary and systemic blood pressures, which may dramatically affect the child's hemodynamic status depending on the child's type of CHD (O'Brien, Evangelista, Green, & Uzark, 2013). Risk of arrhythmia and other cardiovascular morbidities should be evaluated by the child's cardiologist prior to increasing daily activity (Longmuir et al., 2013). Implications concerning sports participation often changes over time according to the seemingly endless advancement of evidence-based research procedures and outcomes. Any physical restrictions should be based on the child's diagnosis, recent therapies or surgeries, disease severity, residual cardiac concerns, and potential risks for harm, as well as according to the most recent evidence-based research findings.

Developing an age-appropriate, medically safe, and individually interesting plan within the boundaries of their abilities requires collaboration between the child, the family, and their healthcare providers (Longmuir et al., 2013). Children living with CHD may have limited aerobic capacity directly related to their compromised cardiac output or decreased oxygenation levels. This limited aerobic capability can influence their ability to participate in many activities that children are typically involved in with their friends and family members. These children often do not want to discuss their physical limitations or how they are different from their peers (Bjorbaekmo & Engelsrud, 2008). Children with CHD realize that participating in demanding physical activities may hinder their ability to participate in required educational activities. Bjorbaekmo and Engelsrud (2008) noted that "exhaustion influences behavior towards friends and also interferes with play and activities as well as relationship with others" (p. 786). The nurse can help the family to plan physical activities they can participate in together to promote physical fitness and weight management according to the child's abilities. The school nurse may also partner with the cardiologist, physical education teacher, the child, and the parents in the development of measurable goals, such as reaching a prescribed target heart rate goal through walking for 10 minutes per day at lunch with a partner, in order to promote exercise and physical well-being.

Table 2: Genetic Syndromes Linked to CHD

Down syndrome (trisomy 21)	Endocardial cushion defects (ASD, VSD, CAVC)
DiGeorge syndrome	Conotruncal defects, IAA, TOF
Turner syndrome	Bicuspid aortic valve Coarctation of the aorta Hypoplastic Left Heart Syndrome
Noonan syndrome	Pulmonary stenosis
Williams syndrome	Aortic and pulmonary valve abnormalities, Peripheral pulmonary stenosis
Marfan syndrome	Aortic abnormalities
Trisomy 18	Conotruncal defects, Double Outlet Right Ventricle, VSD, TOF, CAVC
Trisomy 13	Conotruncal defects, Double Outlet Right Ventricle, VSD, TOF, CAVC



Including the child early in healthcare and education about their chronic condition will improve self-care and accountability for their health in the future.

Dental Health

Dental care is an important aspect of a child's overall health, and this is of particular importance to the child with CHD. Poor dental hygiene increases the risk of endocarditis in the child with CHD (Di Filippo, 2012). The American Academy of Pediatric Dentistry (AAPD) (2013) recommends dental checkups every 6 months for the school-age child. Parents should adhere to the recommended twice-a-year dental examinations to ensure their child's dental health is monitored and maintained. There has been significant debate through the years in using antibiotic prophylaxis to prevent subacute bacterial endocarditis (SBE) for routine dental procedures (AAPD, 2013). The AHA has recently revised recommendations regarding SBE prophylaxis (2013). Recommendations for procedures that do not require SBE prophylaxis are presented in Table 3. SBE prophylaxis is required for unrepaired

cyanotic CHD, transplant patients, those with prosthetic materials or devices, or with history of infective endocarditis (AHA, 2013). The nurse must provide families with anticipatory guidance regarding oral health in the interest of establishing healthy habits early in the child's life.

Immunizations

Immunizations are often a topic of discussion in children with CHD (Woodward, 2011). Vaccinations should be given according to the American Academy of Pediatrics (AAP) recommendations (AAP, 2014a). Use of the influenza vaccination is currently recommended for all children with CHD (AAP, 2014a). Updated guidelines for immunization against respiratory syncytial virus were published in August of 2014, reflecting a significant change in recommendations for children with CHD. Palivizumab prophylaxis is recommended only for those children less than 12 months of age with hemodynamically significant CHD (AAP, 2014b).

Nurses must be aware of additional types of CHD and related syndromes when discussing vaccinations with families (Table 2). A direct relation to the immune system and its inability to function correctly characterizes these syndromes. Children with heterotaxy syndrome are afflicted with asplenia or functional asplenia. Children with heterotaxy syndrome are at significant risk for life-threatening bacterial infection due to their dysfunctional or absent spleen (Prendiville, Barton, Thompson, Fink, & Holmes, 2010). These children require daily administration of antibiotics in order to prevent sepsis (Prendiville et al., 2010). Children who have undergone a heart transplant should not receive live virus vaccinations due to their profoundly immunocompromised state. The impaired immunity of children with DiGeorge syndrome is a cause for concern as to whether live vaccines are safe and effective. DiGeorge syndrome, also referred to as 22q deletion syndrome, is a genetic condition that causes a reduced number of T-cell lymphocytes in infants (Al-Sukaiti et al., 2010). This can result in their predisposition to viral, bacterial, and fungal infections. Al-Sukaiti et al. (2010) conclude that the measles, mumps, and rubella vaccination is safe for children with DiGeorge syndrome. However, analyses of participants' immune function prior to and after immunization indicate that these children appear to have difficulty supporting antibody formation over time. Al-Sukaiti et al. (2010) recommend that patients with DiGeorge syndrome should be assessed intermittently for antibody levels and appropriately re-immunized. Nurses must be aware of these issues because immunizations that are intended to protect a child from disease could, in fact, result in significant harm to children with CHD. Nurses should collaborate with families about immunization schedules to ensure the child's health and well-being.

Table 3: The Following Dental Procedures Do NOT Require Endocarditis Prophylaxis

Routine anesthetic injections through noninfected tissue
Taking dental radiographs
Placement of removable prosthodontic or orthodontic appliances
Adjustment of orthodontic appliances
Placement of orthodontic brackets
Shedding of deciduous teeth
Bleeding from trauma to the lips or oral mucosa

Table recreated with information from the American Academy of Pediatric Dentistry (2013)http://www.aapd.org/media/Policies_Guidelines/G_AntibioticProphylaxis.pdf

Health-Related Quality of Life for Children With CHD

Children with serious CHD face a lifetime of possible cardiac issues and concern for their overall health (Bjorbaekmo & Engelsrud, 2008; Uzark et al., 2008). These issues may manifest in numerous ways such as a decline in physical activity and social engagement as well as an overall decrease in psychological well-being (Birks, Sloper, Lewin, & Parsons, 2007). Birks et al. (2007) identified themes from children and adolescents focusing on the physical effects of their condition, its effects on their activities, body image, and other people's response to their condition. An underlying subtheme was the need for assistance from healthcare providers in navigating communication with others related to their CHD (Birks et al., 2007).

Health-Related Quality of Life includes physical, psychological, and social factors affecting child health. In exploring parent and child self-perception of HRQOL, Krol et al. (2003) concluded that parents reported more concerns for their child's health, focusing on vulnerability rather than ability. Similar findings were reported by Uzark et al. (2008). Self-report scores were lower for the CHD population and for the healthy population on physical and psychosocial domains of HRQOL (Uzark et al., 2008). Parent scores were significantly lower than the child self-report (Uzark et al., 2008). Lower HRQOL scores were associated with higher disease severity (Uzark et al., 2008). This may influence all aspects of the child's health and well-being. Parents who view their child as physically vulnerable may arbitrarily limit the child's opportunity to participate in sports, play groups, and other important social events. Nurses can facilitate parent-child interactions by encouraging families to emphasize the positive aspects of their health, instead of focusing on illness and limitations. This may be done with modeling this behavior for the parent, and encouraging conversation about these concepts between the child and the parent. A child with CHD wants to see himself or herself as "normal," just like any other child. Nurses and healthcare providers need to advocate for these children so that others view them as "normal" despite their physical, potential intellectual, and psychosocial limitations. Several studies measuring HRQOL exist in the literature; an in-depth exploration of HRQOL is included in the article by Cantrell and Kelly (2015) in this issue of MCN.

Family Considerations

Children with CHD have varying comorbidities with some requiring frequent or prolonged hospital admissions.

This can lead to separation anxiety, impaired bonding with family members, and behavioral issues as seen in other children with special healthcare needs. Parents who focus on vulnerability may not consistently provide discipline. This may lead to increased turmoil and feelings of resentment from siblings leading to additional stress and frustration. Rempel, Ravindran, Rogers, and Magill-Evans (2013) explored "Parenting under Pressure" in parents of children with CHD. Parenting experiences were identified and recommendations made for healthcare providers to facilitate adjustment to this experience (Rempel et al., 2013). Parents report that ensuring adequate and accurate knowledge and skills for the care of the child, and anticipation of needs in the future is important (Rempel et al., 2013). Table 4 highlights a number of long-term issues children with CHD may contend with during their adolescent and adult life. Families must be aware of these potential issues, and how to prevent or manage complications.

Compliance with medications and therapies among children with chronic illnesses, specifically CHD, is enhanced when the family unit understands their importance and supports the child in adhering to the prescribed treatment plan (Wernovsky et al., 2006). A multidisciplinary care team is extremely helpful in facilitation of care both in and outside the hospital. Nurses, physicians, respiratory therapists, child life specialists, social workers, and chaplains are all part of this multidisciplinary care team. Nurses play a central part in implementing this approach.

It is essential that nursing interventions and patient-family education start as early as possible to adequately empower the child with CHD in dealing with their disease process. Nurses can have a tremendous impact in this realm, as they are essential to preparing the child and their family for current health concerns as well as the educational needs of the child at the appropriate developmental level. Nurses are aware that education must begin early and often if is to have an effect on the patient's level of wellness. Education on CHD, quality of life, and self-care throughout the life span must begin during the school-age period if the child is to have the best opportunity to succeed in assuming responsibility for their own care as adults. Gurvitz et al. (2013) report that more than 50% of children with CHD experience a lapse in follow-up lasting greater than 3 years. Most experience this lapse in late adolescence. Understanding this risk may help nurses better educate patients and families to prevent its occurrence. Collaboration and communication with the parents and the child with CHD is of vital importance to the long-term health and well-being of the child as they move through life.

In addition to implications for nurses in health maintenance, nurses have the ability to provide the child with clear, honest, accurate information according their developmental and intellectual level (Barlow & Ellard, 2004). Inclusion of the school-age child in planning and education will help foster accountability and establish a sense of "normalcy" to their condition relative to their surroundings (Barlow & Ellard, 2004). The school-age child with CHD empowered by education will have the tools to assume responsibility for himself or herself as a young adult with CHD within society.

Table 4: Possible Long-Term Complications of CHD

Need for reoperations/cardiac catheterization
Heart failure/ventricular dysfunction
Hyperviscosity of blood
Stroke/thrombosis
Endocarditis
Rhythm disturbances requiring ablation or pacemaker
Sudden death
Myocardial infarction
Systemic and/or pulmonary hypertension
Renal problems
Exercise limitations
Chronic medications
Need for SBE prophylaxis

The nurse should provide the child with optimistic, yet realistic information about their health to help the child consider their illness in a different manner (Tong & Kools, 2004). Acknowledging their fears, but helping them focus on positive aspects of their accomplishments, friendships, and support systems are important roles for the nurse, particularly the primary inpatient or outpatient nurse who has cared for the child repeatedly (Tong & Kools, 2004). Time allotted during outpatient visits to be able to engage in these formative conversations is helpful, but will need to be handled creatively. Targeted questions, individualized to include patient and family specifics, that review psychosocial features of self-care, may facilitate the discussion (Barlow & Ellard, 2004). The child with CHD should appreciate that the healthcare team values the child's psychosocial well-being as much as the child's physical well-being.

Conclusion

School age, ages 6 through 12 years, is a crucial stage in preparing the child with CHD and their family for the future. They require individualized care plans according to their physical, developmental, educational, and psychosocial needs. Regular health maintenance activities such as developmental support, healthy weight management, dental care, and immunizations must be addressed in light of their cardiovascular sequelae and current healthcare needs. Nurses are instrumental in organizing the multidisciplinary approach that is essential in the care of the school-age child with CHD. This multidisciplinary approach is the foundation for their successful transition into adulthood as healthy, well-adjusted survivors of CHD.

Future directions for nursing and research include exploration of methods for successful transition from pediatric cardiology care to adult cardiology. Nurses are vital in helping children to begin assuming care for themselves in a gradual, safe, educated manner. Parents

and children with CHD need education about the child's specific needs and must work together with nurses if this goal is to be achieved. Type of care and follow-up required may be determined by the type of CHD the child has as well as their current state of health. Although the cause of CHD remains unknown, it remains the most common birth defect affecting infants and, now, adults due to the significant improvements in healthcare. Nurses must rise to this challenge and promote the healthiest and best quality of life for children and families living with CHD. ✣

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