

# Pediatric Patients With Congenital Heart Disease

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## ABSTRACT

Congenital heart disease is a lifelong disease that results from a heart defect or structural anomaly. Signs and symptoms of heart disease vary by age and developmental stage of the pediatric patient. Thorough history and physical examination guide the nurse practitioner to determine the need for further evaluation, referral, and collaboration with acute care and cardiac specialists to manage this complex chronic illness. Using an illustrative case, this article highlights the signs and symptoms concerning for congenital heart disease; suggests available resources; and encourages frequent communication and collaboration to improve outcomes of this diverse, vulnerable population throughout the life span.

**Keywords:** aortic coarctation, congenital heart disease, pediatric cardiac

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Congenital heart disease (CHD) is a lifelong disease that results from a heart defect or structural anomaly at birth. CHD is the most common birth defect, with approximately 1 in 100 infants born in the United States with it each year.<sup>1-3</sup> With advances in diagnostic accuracy, specialty clinical care, and critical congenital heart screening, many congenital heart defects are diagnosed prenatally or soon after birth.<sup>1-3</sup>

Plans are made for infants with a prenatal diagnosis of CHD to be delivered in centers where complex cardiac care is available. State-based birth defect programs track newborns and young children diagnosed with CHD, and the Centers for Disease Control and Prevention is working with various state departments of health to track these individuals throughout their lifetime. The population of individuals with CHD is growing, and this population has complex health care needs throughout their life span.<sup>2</sup> Primary and acute care provider collaboration and communication will lead to an improved understanding of the unique needs of this population.<sup>4</sup> A 2017 joint policy statement by the American Academy of Pediatrics (AAP) and American College of Cardiology (ACC) was developed through collaboration with the adult congenital and pediatric cardiology council of the ACC and the AAP committee on practice and

ambulatory medicine to provide an organized resource for primary care providers who manage patients and families with CHD through various life stages.<sup>5</sup> Using a well-child visit case presentation, this article highlights the signs and symptoms concerning for pediatric CHD, discusses a recently released AAP/ACC policy statement,<sup>5</sup> and encourages a team approach for managing pediatric patients with heart disease.

## CASE PRESENTATION

An illustrative case of a pediatric patient who presents for a well-child visit and is found to have signs and symptoms concerning for pediatric CHD is presented in [Boxes 1](#) and [2](#). Physical examination and vital signs from the case are included.

When reviewing the history and physical examination findings for the case study, the nurse practitioner (NP) should address each of the following questions: (1) which, if any of the findings, suggest compromised cardiac function versus expected findings with *normal* growth and development; (2) does this patient need a referral to pediatric cardiology and, if so, should this be an urgent referral or a next available appointment; (3) what collaboration is necessary with the NP, patient family, and pediatric cardiology service for this patient and any patient

### Box 1. Well Child Visit: Case presentation.

HPI: A 4.5-month-old male infant with no significant past medical history or birth history presents to the clinic with his parents for a 4-month well-child checkup.<sup>6</sup> The parents are enthusiastic and positive about their infant's development and their bonding as a family, and they have no specific concerns for this visit. They report that the child is "babbling more, smiles, often has his hands in his mouth, and drools a lot."

PMH/birth history: term infant, G1P1. No prenatal concerns, spontaneous vaginal delivery, Apgar scores of 8 at 1 minute and 9 at 5 minutes. Infant passed the critical congenital heart screen at DOL 1 and was discharged home.

Birth statistics: weight = 3.4 kg, length = 48 cm, head circumference = 36 cm

Past surgical history: circumcision on DOL 1 without complications

Family history: no family history of heart disease or death in childhood

Social history: lives with parents, both students and employed full-time. Mother plans to stay home with infant until infant is 6 months old, and then the infant will attend day care.

Allergies and medications: none

Sleep history: Sleeps in crib. Put to sleep on back. No bottles in crib.

Feeding history: breastfed for 3 months without difficulty. Now bottle-feeding (8-oz bottles 4-5 a day). No reports of increased work of breathing, diaphoresis, choking, or fatigue with feeds.

Developmental screen/ROS<sup>6</sup>: generally active, sleeps well, alert, playful, easily consolable. No diaphoresis, tachypnea, or increased work of breathing during feeds or when crying.

Social: Turns head to voice and visually follows parents around room.

Language: Babbling, "ba," laughs

Gross motor: rolls front to back and back to front, lifts up on arms from front lying, no head lag

Fine motor: reaches for objects, brings hands together for objects

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*Apgar = Appearance, Pulse, Grimace, and Respiration; DOL = day of life; G1P1 = 1 pregnancy, 1 delivery; ROS = review of systems.*

with a history of a congenital heart defect before and after repair; and (4) what is the anticipated growth and development and disease trajectory for a young patient with CHD.

#### Tips for History Taking

This case study represents a well-child, or health supervision, visit. Well-child checkups provide an opportunity for the NP to evaluate patients at defined times to monitor growth and development. The goals for these surveillance visits include disease detection, disease prevention, health promotion, and anticipatory guidance.<sup>7</sup> There are several findings from the patient's history in this case study that are reassuring and suggest that this patient does not have compromised cardiac function. Monitoring a child's growth is the best indication of that child's overall

health, and optimal nutrition improves development overall.<sup>8,9</sup> The table of vital statistics presented in [Box 2](#) shows this child is growing as expected. It is reassuring in this case presentation that the caregiver does not report dyspnea, diaphoresis, increased work of breathing, or fatigue when the infant feeds.

Caregivers of infants with CHD may report feeding difficulties. There are multiple factors that contribute to feeding difficulty in patients with congenital heart defects including the type of defect, the type of repair or palliation of the defect, and developmental factors that result from hospitalization during infancy.<sup>9,10</sup> Patients with compromised cardiac function often can only tolerate small volumes of feeds and may appear distressed when eating. As an example, a patient with a ventricular septal defect may become tachypneic and even diaphoretic when eating. Thus, a careful feeding

### Box 2. Findings From the Physical Examination for Case Study

Age	Weight (kg)	Length (cm)	Head Circumference (cm)
Birth	3.4	48	36
1 mo	4.5	54	37.8
2 mo	5.6	58	39.6
4 mo	7.2	64	42

Interpretation of trend                      Has shown steady growth and remained at 50th percentile for weight and length since birth

Vital signs: heart rate = 160 (when held by mother, calm), respiratory rate = 36,  
SpO<sub>2</sub> = 98%, blood pressure not taken (not indicated until 3 y)<sup>6,7</sup>

General: well appearing, well-developed infant male, interactive, smiling, and babbling during examination

HEENT: normocephalic; atraumatic, anterior fontanel open soft and flat; oral pharynx clear; pupils equal, round, and reactive to light

CV<sup>5</sup>: tachycardic at rest; regular rhythm; normal S1 and S2 and 2/6 harsh, systolic ejection murmur best heard at the left lower sternal border and radiating to the back

Lungs: good air movement throughout, no abdominal breathing or nasal flaring; clear to auscultation, without crackles or wheeze.

Abdomen: soft, nontender, nondistended, no hepatosplenomegaly, active bowel sounds

GU: circumcised male, no scrotal edema

Extremities: warm, < 2-second capillary refill to fingers and toes, no clubbing or cyanosis; bilateral brachial pulses 2+, bilateral femoral pulses 1+ and unable to palpate pedal pulses

CV = cardiovascular; GU = genitourinary; HEENT = head, eyes, ears, nose, throat; SpO<sub>2</sub> = peripheral capillary oxygen saturation.

history and monitoring an infant's growth will provide valuable insight to any infant's cardiac function. The signs and symptoms of compromised cardiac function or heart failure (HF) are different in pediatric patients compared with adults with HF. Furthermore, the clinical presentation of HF varies by age and developmental stage of the pediatric patient. Also, clinical presentation of HF varies with the patient's cardiac physiology and history (the type of cardiac defect, the residual defect, cardiac repair, or palliation).

In pediatrics, the pathophysiology of HF can occur in cases of excessive preload or afterload, usually as the result of a structural anomaly from CHD (such as a ventricular septal defect or coarctation of the aorta) or residual defects after the repair or palliation of a complex congenital heart defect (such as hypoplastic left heart syndrome or atrioventricular

septal defect). For example, patients with ventricular septal defects and/or a patent ductus arteriosus have *shunts* that cause increased volume on the left side of the heart, or excessive preload. Because pulmonary vascular resistance is lower than systemic vascular resistance, blood flow is left to right across these shunts and causes excessive pulmonary blood flow relative to systemic blood flow, which ultimately contributes to the development of HF.<sup>11</sup> Infants exhibit signs of HF including feeding intolerance, dyspnea, early fatigue while eating, decreased volume tolerance, and diaphoresis. In addition, infants and children with HF will have tachypnea, mild to severe work of breathing, retractions, and grunting with exertion (eating, crying, and playing). Findings from their physical examination will reveal tachycardia, gallop, and hepatomegaly.<sup>11</sup>

### Tips for the Physical Examination

When conducting the physical examination, the NP should assess the heart rate (HR) (checking for tachycardia based on age) and the regularity, strength, and presence of peripheral pulses, blood pressure, and auscultate heart sounds (checking for murmurs). In the case presented here, the patient's HR is 160 beats/min at rest. Recalling that cardiac output is a function of HR and stroke volume, an HR of 160 is elevated for a 4.5-month-old who is well hydrated and afebrile and is content being held by a known caregiver.<sup>12</sup> Thus, the NP should ask questions during the history and review of systems to possibly explain the abnormal HR. For example, asking questions about how the patient looks and acts during periods of increased activity or exertion (feeding or playing) or high metabolic demand (fever or identified illness) will provide the NP with insight into the patient's heart function.<sup>13</sup>

An abnormal HR or an irregular heart rhythm and decreased contractility may not generate enough cardiac output to meet tissue demands, which could lead to worsening heart function or HF. For example, consider a patient with supraventricular tachycardia whose HR is so fast there is reduced time for ventricular filling, and, therefore, the stroke volume is decreased. Thus, tachycardia may both contribute to and/or be a sign of HF in children.<sup>5,11,14</sup>

According to the recommendations by the AAP<sup>7</sup> and the Bright Futures periodicity table,<sup>6</sup> an evaluation of a pediatric patient's blood pressure is not routinely indicated until the child is 3 years old, unless the patient has specific risk conditions. There was no blood pressure provided in the case. However, an evaluation of the patient's pulses revealed a difference in pulse quality between the upper and lower extremities. Strong pulses were noted in the upper extremities with weak or absent femoral and lower extremity pulses, which may be concerning for left ventricular outflow obstruction, specifically, coarctation of the aorta. Patients with coarctation of the aorta will also have hypertension and a difference of 20 mm Hg between upper and lower extremity blood pressures, with blood pressures in the upper extremity higher than blood pressures in the lower extremities.<sup>1,5,15,16</sup>

Auscultating heart sounds in pediatric patients can be challenging, especially if the patient has CHD. In addition to tachycardia at rest with a regular rhythm, the cardiac examination in the case included a normal S1, S2, and a 2/6 harsh, systolic ejection murmur best heard at the left lower sternal border, radiating to the back, which did not change with patient positioning. It can be a challenge to discern this level of detail about the heart sounds when performing an examination on an infant or child whose HR is high and who is most likely not sitting or lying quietly on an examination table (like an adult patient). Despite the patient being afebrile and without anemia (indicating the patient was not in a high-output state), the murmur described in the patient in the case is concerning, particularly because the patient had other physical examination findings that suggested cardiac etiology (ie, tachycardia and decreased lower extremity pulses).

A heart murmur is just 1 physical examination finding that must be interpreted in the context of the patient's age and presentation, history (specifically feeding history and evaluation for signs of decreased function), physical examination (with attention to signs of decreased cardiac output or cardiac compromise), and overall growth and health. In addition to detecting the presence of a murmur, the timing of the murmur (systole or diastole), the specific location where the murmur is loudest, and the quality of the sound with patient positioning will help the NP distinguish between an innocent and pathologic murmur.<sup>15,16</sup> Innocent murmurs are more likely to be discovered when patients are in a high-output state (such as fever or anemia), are usually noted during systole, and become louder when the patient changes position. An innocent murmur that radiates to the back is a pulmonary flow murmur, most often discovered when a patient is in a high-output state, is heard in the area of the pulmonary valve (left upper sternal border), radiates to the back and axilla bilaterally, and changes in intensity with the patient's respiratory pattern and positioning.<sup>15,16</sup>

Detecting a murmur for the first time on physical examination may cause anxiety for the patient, family, and provider. An identification of a murmur in a child is a common reason for collaboration with cardiology colleagues, often necessitating a referral to

the pediatric cardiology clinic.<sup>16,17</sup> The timing of the referral (immediate, urgent, or first available appointment) depends on the NP's clinical judgment and other concerning history or physical examination findings. Sometimes collaboration over the phone with the cardiology provider will help allay some of the preappointment anxiety.

### Referral to Pediatric Cardiology

An important decision that the NP needs to consider is whether to refer a patient to the pediatric cardiology service if a new murmur or other signs and symptoms consistent with compromised cardiac function are discovered in the history or physical examination. If a referral is indicated, the NP needs to decide if the referral is urgent or if the patient and family can wait until the next available appointment.

When considering the findings in the case study, the patient should be referred to a pediatric cardiologist as soon as possible. Although this patient's general appearance, growth, and feeding history are reassuring and consistent with expected growth and development of a healthy child,<sup>6</sup> the presence of tachycardia, weak femoral pulses, and the murmur are findings consistent with coarctation of the aorta. Hypertension noted on examination with higher blood pressures in the upper extremities compared with lower blood pressures in the lower extremities is also consistent with coarctation of the aorta. Because there is a constellation of symptoms (tachycardia, decreased pulses, and a harsh systolic murmur radiating and unchanged by patient positioning) and the patient has vital sign changes consistent with early HF (tachycardia), urgent referral to pediatric cardiology is warranted for further diagnostic evaluation and planning for surgical intervention. If the patient had an isolated systolic murmur without other physical examination findings and a reassuring growth pattern, a feeding history negative for tachypnea, diaphoresis, or increased work of breathing, there would be less urgency for the referral. The NP may choose to schedule a follow-up visit to evaluate for additional cardiac symptoms and reevaluate the murmur, collaborate with an acute care or pediatric cardiology colleague, or suggest a follow-up appointment with pediatric cardiology, but there is less indication for immediate referral to a pediatric cardiac service.

### Collaboration With Acute Care and Cardiology Specialty Providers

The NP in the case provided has an opportunity to help the family or caregiver prepare for their visit to the cardiac clinic. When working with pediatric patients, the NP needs to consider the patient-family-provider relationship because this is unique. In the case presented, the referral and subsequent visit to the pediatric cardiology clinic is the first opportunity for the family or caregiver to meet the pediatric cardiology specialists and acute care providers who will join the NP, the patient, and family/caregiver through the next stages of diagnosis and management of coarctation of the aorta.

In this case, the patient's abnormal findings were noted during a well-child checkup, and he was generally healthy. Because he was healthy at diagnosis and had a discrete coarctation without other defects, he was a candidate for surgical repair that involved removing the narrowed segment and end-to-end anastomosis of the aorta. This was done through a left thoracotomy, and the patient did not have to be put on cardiopulmonary bypass. The patient had expected convalescence in the postoperative period, although he remained hypertensive. Hypertension after repair of coarctation is not uncommon.<sup>5,15,18</sup> He was discharged home with his parents on postoperative day 6 with a prescription for an antihypertensive agent and an appointment in the cardiac clinic in 2 days, and a summary of his hospital course was sent to his primary care provider, an NP in the same hospital system. He had a posthospitalization visit with his NP 1 week after surgery.

For patients with CHD, the surgical intervention, the timing of surgical intervention, and the length of hospitalization and recovery depend on many factors including the complexity of the cardiac defect, the degree of HF, and the overall health of the patient in the preoperative period.<sup>5,15</sup> The case presented represents a patient diagnosed, after ductal closure, with distinct coarctation of the aorta with preserved ventricular function. Coarctation of the aorta is not always a distinct narrowing of 1 specific area in the aorta. There are a variety of malformations that may affect the aortic arch and arterial vasculature. Some of these include complete interruption of the aortic arch, segments of arch hypoplasia, and discrete

coarctation. Many congenital heart defects are not isolated to a single defect. With coarctation of the aorta, there may be other left-sided cardiac anomalies that contribute to HF from increased afterload and left ventricular outflow obstruction such as bicuspid aortic valve or other mitral or aortic valve anomalies. If the patient had any of these conditions, the presentation would be very different and would include signs of HF and poor cardiac output. Critical coarctation and other ductal-dependent critical congenital heart defects are often diagnosed during prenatal ultrasound or in the newborn period with critical congenital heart defect screening.<sup>1-3,5</sup> On the other end of the spectrum, some patients with coarctation of the aorta are diagnosed in adolescence or young adulthood when they are being evaluated for hypertension. Although these patients are hypertensive, they present without a significant blood pressure difference in the upper and lower extremities because of collateral circulation that has developed over time.<sup>13</sup>

It goes beyond the scope of this article to try to describe all of the signs and symptoms associated with congenital heart defects and the repair of these defects. This case includes tachycardia and findings consistent with isolated coarctation. Also, the purpose of this case was to present a history with pertinent positive and negative findings for HF. In this case, the patient was eating well without tachypnea, diaphoresis, fatigue, or feeding intolerance with no signs of respiratory distress, tachypnea, retractions, or hepatomegaly on the physical examination.

### **Collaboration and Coordination During Transitions of Care**

In the case presentation, through collaboration and ongoing communication, the referring NP is an integral part of this patient's entire care team. Together, the team including the referring NP, cardiology, and other acute care NPs will manage the complex health care needs of the patient and support the patient and family/caregiver during the workup of CHD in the hospital, in the pediatric cardiology clinic, and as the patient transitions back into the community and throughout his lifetime.<sup>4,10</sup>

Several studies have attempted to describe risk factors associated with long-term postdischarge

adverse effects after hospitalization for surgery for repair or palliation of congenital heart defects.<sup>19-21</sup>

This is important because pediatric patients with CHD are a highly vulnerable population with complex health care needs that are multifactorial. Just as important as clear communication at the time of the initial referral to the pediatric cardiology service is the communication from the pediatric cardiologist and acute care team back to the primary care provider through the discharge summary. The discharge summary should include a description of the patient's hospital course, physical examination findings at the time of discharge compared with baseline vital signs and oxygen saturation levels, medications at the time of discharge, immunization recommendations and risks for infection, recommendations specific to the patient's cardiac defect, and a plan for anticipated adverse outcomes and follow-up with the pediatric cardiology service.<sup>10</sup> Risk factors for adverse outcomes such as death and unplanned readmission in the first year after discharge from hospitalization for surgery for repair or palliation of complex congenital heart defects include age at surgery (in the newborn period, infancy, or older infant), complexity of the defect and surgical intervention performed (complete repair, repair with residual defects, and/or palliative interventions), and whether there were postoperative feeding difficulties. These risk factors have been previously described in a systematic review of patients with complex single-ventricle cardiac diagnoses.<sup>21</sup> However, the NP should note that patients with CHD are a diverse, heterogeneous population with complex chronic illness. The needs of these patients and families go far beyond those that are specific to the cardiac physiology and management plan. Furthermore, the interdisciplinary team, including the NP, must also consider the psychosocial and financial effect and stress of hospitalization on the family or caregiver as well as the long-term effects and management of CHD.<sup>4,10</sup>

### **CONCLUSIONS**

Pediatric NPs have education and experience with disease detection, prevention and screening, evaluation, diagnosis, management, and anticipatory guidance to support optimal health of children and their families in their medical homes and communities.

Furthermore, NPs are uniquely positioned to provide support and care coordination for patients with CHD across their life span. The joint policy statement by the AAP and ACC recognizes that the care of this highly vulnerable population is multifaceted, and the policy statement provides a comprehensive set of guidelines for managing patients with CHD inclusive of screening (pulse oximetry and genetic screening), diagnosis, posthospitalization discharge, and beyond throughout the patient's life span.<sup>5</sup> This policy statement also suggests resources available for families of children with CHD. The anticipated clinical and psychosocial problems associated with CHD have also been described using the pediatric age group as an organizational framework.<sup>10</sup> In a commentary that accompanied the release of the policy statement, the lead author recognized the care and support provided by the primary care providers (pediatricians and NPs) and called for frequent communication and collaboration among all care providers to improve outcomes of this vulnerable population throughout the life span.<sup>22</sup> Although the origin of the proverb is debatable, the sentiment and call for social responsibility is true; it takes a village to raise a child. It takes a village and *exceptional* collaboration and communication to care for children with cardiac disease, especially during times of transition. **JNP**

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1555-4155/18/\$ see front matter  
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<https://doi.org/10.1016/j.nurpra.2018.10.017>