An Overview of Congenital and Rheumatic Heart Disease in Refugee Children

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Abstract

Congenital heart disease (CHD) exists on a spectrum and impacts approximately 1% of children born worldwide. Refugee children with CHD are often disproportionately impacted due to tumultuous circumstances and lack of access to consistent or adequate healthcare during early life. This lack of access to healthcare also increases the risk of rheumatic heart disease, which has been largely eradicated in developed countries. Overseas medical examinations and new arrival health screenings by a primary care clinician are crucial to identify children with known or previously unidentified heart disease and to efficiently coordinate both acute and long-term care. In addition to providing routine childhood health maintenance, a primary care clinic also serves as a medical home and can help families navigate the many challenges of an unfamiliar healthcare system.

Patient vignette

AB* was born overseas and was diagnosed with tricuspid atresia at 1 month of age. At 2 months of age, he underwent his first open-heart surgery, a bidirectional Glenn procedure, in a nearby country. His family then lived in a refugee camp for several years before they were ultimately resettled to the United States. His overseas medical examination arrived at the local health department shortly before he did and allowed the hospital to plan for his arrival.

*Patient's actual initials withheld for confidentiality.

Congenital heart disease

Congenital heart disease (CHD) is among the most commonly diagnosed congenital defects, affecting 0.8-1.2% of infants born globally.[1,2] Ventricular and atrial septal defects are the most common congenital heart defects, though CHD encompasses a wide range of diagnoses with drastically different implications for morbidity and mortality.[3] A small, though still notable, portion of infants are born with complex heart defects such as tricuspid atresia that require surgical intervention in early infancy. Some defects can be repaired, while others are treated with surgical palliation. Children with simpler lesions may live relatively normal lives, but those with complex anatomy or additional comorbidities depend on lifelong care from a multidisciplinary health care team. It is important to note that 20-30% of individuals with CHD have at least one physical, developmental, or cognitive comorbidity.[4]

It is unsurprising that children in developing countries, and by extension those who arrive to developed countries as refugees, are disproportionately impacted. In the United States and other developed countries, many congenital heart defects are identified during routine prenatal screening and are further characterized prior to delivery via fetal echocardiography.[5] These children are closely followed by cardiology during the peripartum period and beyond, which allows for medication management and optimization of surgical timing. The incidence of CHD amongst refugees has not been well studied, but it is likely similar. Etiology is often multifactorial, including both environmental and genetic causes. It is

important to note that consanguinity, which is common in some refugee subgroups, increases the risk of heritable disorders including some forms of CHD.[6,7] Regardless of the cause, many of these children are identified later in infancy or childhood once problems arise or when they are evaluated by a healthcare professional. Some may receive surgical or medical treatment overseas, though this is not universally the case.

Rheumatic heart disease

Rheumatic fever has been largely eradicated in developed countries due to advances in treatment of streptococcal pharyngitis, but it remains the leading cause of acquired heart disease in children globally and an important cause of pediatric heart failure cases in endemic areas.[8,9] Rheumatic fever and its sequelae are most prevalent in Sub-Saharan Africa but are a devastating reality in many other war-torn or impoverished countries where access to medical care is limited or inconsistent. As a result, refugees arriving from these regions may be at risk. Rheumatic heart disease can manifest in a variety of ways including myocarditis, arrhythmias, heart failure, or valve disease. The left sided heart valves are most commonly affected, with damage leading to regurgitation, stenosis, or a combination of the two. Mitral regurgitation is the most common clinical manifestation of rheumatic heart disease in children and young people. The tricuspid valve can be affected, but this is not usually an isolated finding. The pulmonary valve is rarely affected.[10]

Screening and identification of CHD in refugee children

Overseas medical examination

All refugees, including children, are required to have an overseas medical examination prior to arrival in the United States (typically 3-6 months in advance).[11] In addition to a review of vaccination records and communicable disease screening, the overseas medical examination includes a physical examination by a panel physician and documentation of any known medical history. “Class A” conditions such as active tuberculosis preclude admission to the United States. CHD is categorized as a “Class B” condition, a term used to describe any medical condition that does not preclude entry but may require post-arrival follow-up.[12] A “Significant Medical Condition” form should accompany the overseas medical examination form of any individual with significant health needs who will need prompt follow-up upon arrival in the United States. This document many also identify individuals in need of additional services such as equipment or a medical escort for travel. The CDC receives overseas medical examinations and will notify the appropriate health department when an individual arrives with a medical condition requiring prompt attention.[13] It should be noted that refugees arriving directly from their country of origin, such as parolees arriving from Afghanistan, will not have had an overseas medical examination.

New-arrival health assessment

Refugees then undergo a health assessment shortly after arrival in the United States. This initial assessment may occur via the health department, though ideally refugees are quickly established within a primary care practice that can serve as a medical home within a new healthcare system.[13] Unsurprisingly, vital signs are a crucial component of the physical exam for children arriving with known CHD. Special attention should also be paid to the cardiac exam as well as any potential stigmata of cardiac disease such as hepatomegaly or digital clubbing. While some cardiac lesions create a murmur, this is not universally true.

A detailed family history is also important with special emphasis placed on sudden cardiac death, CHD, and arrythmias. Children with known or suspected cardiac disease, regardless of etiology, should be seen by both a primary care physician and a pediatric cardiologist, though the timing of these appointments will vary based on specific diagnoses and clinical stability.

Unique considerations for the primary care physician

Health maintenance is a crucial aspect of medical care for children with CHD, and especially those children who may ultimately require surgical intervention. Increased metabolic demand frequently leads to poor growth, which should be monitored closely.[14] This susceptibility to poor growth may also be compounded by comorbidities frequently seen in the refugee population such as nutritional deficiencies and parasitic gastrointestinal infections.[15,16] All children, but especially those with significant cardiac disease, should be evaluated for dental caries or infection. Many refugee children arrive to the United States without proper dental hygiene and having never seen a dentist. Significant dental caries often need to be addressed prior to major cardiac interventions to minimize infection risk.[17] Additionally, as refugees are not statutorily required to be vaccinated prior to arrival in the United Sates, care should be taken to make sure that routine childhood vaccines are up to date.[12]

Barriers to care

The families and caregivers of children with complex medical needs including CHD face many challenges while accessing medical care. Refugee families in particular find themselves navigating a complicated and often fragmented healthcare system while simultaneously learning a new culture and language. Some are well-educated, while others may be illiterate in their native language. Health literacy is highly variable. The frequency of appointments can be challenging for those without reliable transportation, and finding new locations within the hospital may be difficult for those unable to read signage. In response to these challenges, some health systems have created dedicated primary care clinics that serve as a medical home for refugees and make both clinical and support services more accessible. For example, the International Family Medicine Clinic (IFMC) at the University of Virginia provides support services and care navigation through a dedicated nurse care coordinator, social worker, and case manager/patient advocate.[18] To further address subspecialty needs, one health system in Texas started a monthly pediatric cardiology clinic within the already-existing framework of a federally qualified health center serving a large refugee community.[19] By doing so, services were consolidated and patients were seen in a familiar setting. While these models may not be universally possible, they highlight the importance of a collaborative and interprofessional approach between primary care providers, subspecialists, and other healthcare professionals when caring for refugee children with complex needs.

Vignette continued

Now 6 years old, AB was seen in the IFMC less than a week after he arrived in the United States for a comprehensive intake evaluation, baseline laboratory studies, and to establish care within the clinic that would function as his medical home. A few days later he was also seen by a pediatric cardiologist, who performed an echocardiogram to further define his complex heart disease and determine next steps. AB was seen by developmental pediatrics for developmental concerns and

his extensive dental caries were addressed to minimize perioperative infection risk. A multidisciplinary care coordination meeting was held with AB's parents prior to his second open-heart surgery, a Fontan procedure. Due to the coordinated efforts of many and despite various challenges, AB has done relatively well.

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