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ORIGINAL ARTICLE

Heart Disease in Syrian Refugee Children: Experience at Jordan University Hospital

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Abstract

BACKGROUND Since March 2011, an estimated 600,000 Syrian refugees crossed into Jordan, of which 52% were children. Demand for health care is overwhelming. The burden of heart disease in Syrian refugee children is not known. The aim of this study WAS to describe heart disease in Syrian refugee children in terms of diagnoses, presentation, outcome, and funding sources for treatment.

METHODS From April 1, 2012 to April 30, 2014, data on Syrian refugee children who were referred to the Pediatric Cardiology Department at Jordan University Hospital and were found to have heart disease was recorded. In this study, we describe diagnoses, presentations, complications, and mortality. We discuss therapeutic procedures and their funding sources. Patients were followed until July 31, 2014.

FINDINGS In all, 119 children, median age 2 years (6 days to 16 years), were diagnosed with heart disease. At presentation, 37% had failure to thrive, 13% had severe complications, and 32% of cyanotic patients had severe hypoxia with oxygen saturation of <70%. Mortality rate was 14% by end of follow up. Of 73 surgical procedures recommended, only 28 were funded and performed; others have been waiting for a median of 223 days (35-534 days). Funding for procedures came from multiple sources; including the United Nations, governmental and nongovernmental organizations, and individual donations.

CONCLUSION Heart disease in Syrian refugee children constitutes a major problem for both patients and health systems of host countries. Late presentation and diagnosis, high rate of complications, suboptimal living conditions, lack of funding, shortage of specialized centers and personnel, and high mortality rates are among the major challenges facing this patient population.

KEY WORDS Congenital heart disease, heart disease, pediatric heart disease, Syrian crisis, Syrian refugees

INTRODUCTION

Problem Statement. Since March 2011, Syria has suffered from political turmoil forcing millions of Syrians to cross international borders. Approximately 2.9 million Syrians have become registered refugees with the United Nations High Commissioner for Refugees (UNHCR). Of those, 600,000 are registered in Jordan alone. An estimated 52% (310,000) of refugees are age <18 years.[1] Children with heart disease among the refugee population require specialized care. In this study, we focus

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on the burden of heart disease in this patient population.

How Syrian Refugees Receive Health Care in Jordan. For their health care in Jordan, Syrian refugees registered at refugee camps such as Al-Zaatari Refugee Camp, the largest in Jordan with >85,000 refugees,[1] have access to mobile health clinics set up by the Jordanian Ministry of Health and various nongovernmental organizations (NGOs) and UN agencies. Refugees outside of refugee camps primarily access existing government health centers, some of which are funded and maintained by NGOs and UN agencies.[2,3]

For primary health care, health centers both inside camps and major cities provide services to Syrian refugees free of charge or through a cost-sharing mechanism, organized by the UNHCR through the Jordan Health Aid Society. When it comes to secondary and tertiary health care, refugees must be referred to tertiary health centers located at one of Jordan's major urban centers. This referral process is long and taxing, and patients who are finally referred but still require complex medical or surgical interventions are faced with a difficult situation as the cost of such interventions are seldom covered by the Jordanian host government, NGOs or the UNHCR.[2]

The bulk of data available on health status of Syrian refugees in host countries is compiled by the UNHCR. It includes reports that shed light on who is providing health care to refugees and where that care is being provided.[2] The focus of such reports is mainly on primary health care, thus issues such as pediatric heart disease and congenital anomalies are underreported. There is currently no published data on the burden of pediatric heart disease in this patient population. Regarding global awareness of the health crisis in Syria, the medical community has recently made increasing efforts aimed at highlighting the need to increase funding to support health care of Syrian refugees and their host governments.[4] Jordan's Ministry of Health has repeatedly urged international aid agencies to increase funding to support the country in the face of increasing numbers of Syrian refugees.[3]

When a Syrian refugee child is suspected to have heart disease, referral to a specialized center is carried out as outlined previously. Jordan University Hospital, an academic tertiary health care center located in Amman, the capital city of Jordan, was the main site of referral during the study period.

Objectives. The aim of this study was to describe heart disease in Syrian refugee children in terms of diagnoses, presentation, and outcome including mortality and complications. We also report the different sources of funding for patients who underwent treatment procedures.

METHODS

Patients and data. This study included Syrian refugee children (aged 0-18 years) who visited the Pediatric Cardiology Department at Jordan University Hospital between April 1, 2012 and April 30, 2014, and were found to have heart disease. Diagnosis was established using multiple modalities, including history, physical examination, and electro- and echocardiographic studies. Some diagnoses were confirmed by cardiac catheterization. Prospective data was recorded including demographics, birth country, cardiac diagnosis, prior diagnosis or treatment in Syria, and complications if present. We also recorded the type of therapeutic procedures recommended, date and type of procedures if performed, and funding sources. Patients were followed until July 31, 2014. The study protocol was approved by the institutional ethical committee. Verbal consent was obtained from the participants or their guardians when required by age.

Pediatric Heart Disease Definition. Congenital heart disease is defined as an abnormality in cardio-circulatory structure or function that is present at birth, even if it is discovered much later. A wide range of abnormalities is included in this definition. It is worth noting that heart rhythm abnormalities and cardiomyopathies are not usually included in this definition, but we have included data on patients with those conditions, to encompass all types of pediatric heart disease in Syrian refugee children.

Categorization of Patients According to Severity. For purpose of data analysis and discussion of outcomes, patients were classified into 4 categories, based on their need for follow-up and the number of interventional or surgical procedures they are likely to need. The categories were created to reflect severity of disease, and indirectly the cost of treatment and follow-up. In ascending order: Category A included patients who only required regular but infrequent yearly follow-up with no anticipated intervention, such as patients with mild, asymptomatic heart disease and patients with previously well repaired lesions. Category B included patients who required more frequent follow-up, but with no anticipated intervention, such as patients with cardiomyopathy, rhythm anomalies, and symptomatic heart disease