Annals of Global Health
VOL. 82, NO. 2, 2016

ISSN 2214-9996
http://dx.doi.org/10.1016/j.aogh.2015.02.517

ORIGINAL ARTICLE

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

Iyad Al-Ammouri, MD, Fares Ayoub, MD
Al-Jubeiha, Jordan

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

The authors declare that they have no conflicts of interest.

From the University of Jordan, Faculty of Medicine, Department of Pediatric Cardiology, Al-Jubeiha, Jordan (IA-A); University of Jordan, Faculty of Medicine, Amman-Jordan, Al-Jubeiha, Jordan (FA). Address correspondence to I.A-A. (Iyad72@hotmail.com).

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

Annals of Global Health, VOL. 82, NO. 2, 2016
March–April 2016: 300–306

where spontaneous improvement is more likely to occur without intervention. Category C included patients who required a single-stage corrective procedure, whether interventional cardiac catheterization (eg, closure of heart defect or dilation of a valve or a vessel), or surgery (eg, ventricular septal defect repair or tetralogy of Fallot repair). Finally, category D included patients with complex lesions where a single-stage repair is impossible, or those who required both cardiac catheterization and surgical procedures.

RESULTS

Demographics. Between April 1, 2012 and April 30, 2014, a total of 119 Syrian refugee children were diagnosed with heart disease at Jordan University Hospital, 62 (52%) of whom were boys. Mean age at presentation was 4 (±3.9 years), with a median of age of 2 years (range 6 days to 16 years). The majority of patients either resided close to the Jordanian-Syrian border in the northernmost cities of Jordan (n = 41, 34%), or in Al-Zaatari camp (n = 30, 25%). Eighteen patients (15%) resided in Amman, the capital city of Jordan; 14 patients (12%) had no documented place of residence, and the rest (n = 16, 14%) resided in various other cities in Jordan (Fig. 1). Nineteen children (16%) were born in Jordan to refugee parents, whereas 100 patients (84%) were born in Syria and sought refuge in Jordan with their parents. Of those patients born in Syria, 91 (91%) had received a previous diagnosis of heart disease in Syria, 17 of them had already undergone surgical interventions. Of those surgeries performed in Syria, 12 were palliative surgeries where more interventions are still required for definitive treatment and 5 were reparative surgeries, where only regular follow-up is required.

Presentation and Spectrum of Heart Disease. Based on the previously outlined categorization of patients, and in ascending order of severity, 15 patients (12%) were designated as category A, 20 (17%) as category B, 40 (34%) as category C, and 44 (37%) as category D (Table 1).

Patients presented with a wide range of heart disease: 56 (47%) had noncyanotic heart lesions, 55 (46%) had cyanotic heart lesions, and 8 (7%) had miscellaneous disorders (Table 2). Fifteen patients (13%) presented with severe complications: 9 had developed severe pulmonary hypertension, 4 were deemed inoperable, and 5 were considered high-risk surgical candidates. Three patients with complex heart disease presented with bacterial infections (endocarditis, brain abscess, and severe pneumonia), 2 patients presented with decompensated heart failure requiring intensive care management, and 1 developed chronic renal failure requiring dialysis. In all, 44 children (37%) were diagnosed with failure to thrive, defined as body weight <2 SD of the mean for age. As expected,

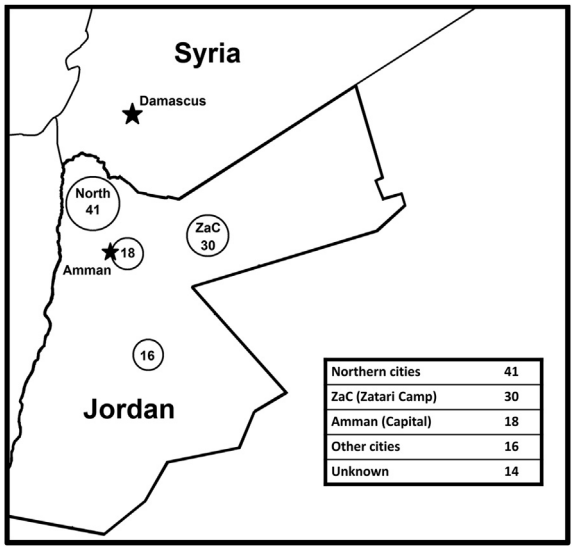

Figure 1. Map of Jordan with Jordanian-Syrian border, displaying the main sites of residence of Syrian refugee children with heart disease, and the number of patients in each site. The location of the main refugee camp is displayed on the map, the capital city of Jordan "Amman", and Syria "Damascus" are represented by stars.

Table 1. Categorization of Heart Disease in Syrian Refugee Children Based on Complexity of Disease

Category	Description	Patients (n)
A	Asymptomatic patients requiring yearly follow-up only	15
B	Patients requiring frequent follow-up, but no interventions	20
C	Patients requiring single reparative procedure	40
D	Patients with complex disease requiring >1 procedure	44
Total		119

category D patients were more likely to have failure to thrive compared with those in the other categories (72% vs 16%, $P = 0.0001$). Of patients with cyanotic heart disease, 17 (32%) presented with severe cyanosis defined as oxygen saturation <70%.

Follow-up. Fourteen patients were lost to follow-up after their initial presentation; attempts to contact the patients were met with no success for various reasons including incorrect contact information, unknown place of residence, or discontinuation of phone number on record. We had complete follow-up data for 105 patients (88%).

Fifteen patients (14%) died during the study period: 9 died awaiting surgical intervention, 3 postoperatively, 2 of the 4 patients who were deemed inoperable due to late presentation died of heart failure, and 1 child with long QT syndrome died suddenly. Of the deaths, 5 occurred at Al-Zaatari camp.

Table 2. Spectrum of Heart Disease in Syrian Refugee Children at Jordan University Hospital

Diagnosis	Number (%)
Noncyanotic congenital heart disease:	56 (47)
Ventricular septal defect	24 (20)
Atrial septal defect	7 (6)
Pulmonary stenosis	7 (6)
Coarctation of Aorta	6 (5)
Patent ductus arteriosus	5 (4)
Subaortic membrane	3 (3)
Interrupted aortic arch	1
Aortic stenosis	1
Cor-triatriatum	1
L-transposition of great arteries	1
Cyanotic congenital heart disease	55 (46)
Tetralogy of Fallot	20 (17)
Double-outlet right ventricle	17 (14)
Pulmonary atresia	7 (6)
Single ventricle	4 (3)
Transposition of great arteries	3 (3)
Ebstein anomaly	2 (2)
Truncus arteriosus	1
Tricuspid atresia	1
Other miscellaneous conditions	8 (7)
Long QT syndrome	3 (3)
Rheumatic heart disease	2 (2)
Cardiomyopathy	2 (2)
Wolff-Parkinson-White syndrome	1

Cardiac surgeries and catheterization recommended and performed by the end of follow-up (July 31, 2014) are outlined in Table 3. Cardiac surgery was recommended for 73 patients, but only 28 (38%) underwent surgery, with a median waiting period of 102 days (range 15-420 days). Those who did not undergo surgeries were waiting for financial coverage (9 died waiting, and 10 were among those who were lost to follow-up); the median waiting time for these patients was 223 days (range 35-534 days) by the end of follow-up. Of those who underwent surgery, 14 did so at Jordan University Hospital (10 surgeries were performed by visiting international teams and 4 by local teams). The median cost of surgery at Jordan University Hospital was $7900. Four patients were sent abroad through NGOs, and the remaining 10 patients who underwent surgery were distributed among 6 other hospitals in Jordan. Most of these surgeries were performed by visiting international teams. Funding sources for those who underwent surgery included individual donations (n = 11), charity organizations (n = 9), and the UNHCR (n = 8).

Cardiac catheterization was indicated in 54 patients, and 37 (69%) underwent the procedure (14 interventional, 23 diagnostic), with a median waiting period of 54 days (range 1-380 days). All catheterization procedures were done at Jordan University Hospital by the local team. Median cost was $1000, and $1800 for diagnostic, and interventional cardiac catheterization, respectively. Funding sources for catheterization procedures included the UNHCR (n = 21), individual donations (n = 11), and patient self-pay (n = 5).

DISCUSSION

Most heart disease in children is congenital, with a minority of acquired disease. The incidence of

Annals of Global Health, VOL. 82, NO. 2, 2016
March–April 2016: 300–306

Table 3. Spectrum of Cardiac Surgeries and Cardiac catheterization Indicated and Performed

Surgical Procedure	Indicated (N = 73)	Performed (N = 28)
Double-outlet right ventricle repair	16	3*
Tetralogy of Fallot repair	15	7
Ventricular septal defect closure	9	2
Pulmonary atresia	7	1†
Atrial septal defect closure	6	4
Coarctation of aorta repair	4	3
Pacemaker insertion	2	2
Others	14	5
Catheterization procedure	**Indicated (N = 54)**	**Performed (N = 37)**
Diagnostic catheterization	39	23
Balloon dilatation of coarctation of aorta	4	4
Balloon valvuloplasty of pulmonary stenosis	4	3
Device closure of patent ductus arteriosus	3	3
Stenting of ductus arteriosus	1	1
Balloon dilatation of narrowed Blalock-Taussig shunt	1	1
Radiofrequency ablation for Wolff-Parkinson-White	1	1
Balloon atrial septostomy (failed)	1	1

* Palliative operations: 2 Glenn operations, 1 Blalock-Taussig shunt operation.
† Palliative operation, Blalock-Taussig shunt.

moderate and severe disease is 6 to 9 per 1000 live births worldwide.[5,6] Many Syrian refugee children with heart disease have fled Syria with their families. Additionally, with a birth rate for Syrian population of 24 per 1000,[7] it is expected that there would be a significant number of infants born with congenital heart disease to refugee parents in Jordan.

Heart disease in children can present in various ways, the most dramatic of which is heart failure and shock in the neonatal period. Such presentations of critical lesions are rare in developed countries today, and are infrequent even in developing countries that provide the minimum of perinatal care. Many patients present incidentally due to an abnormal finding on routine physical examination, yet a number of others present with progressive symptoms. In our time of widespread noninvasive diagnostics, the majority of heart disease in children is detected long before they become symptomatic. In crises however, the situation reverses, and presentations are delayed until heart disease becomes symptomatic or symptoms become so severe that they affect quality of life. Critical presentations, although still rare, could not be assessed in this report because many of these children die within days of being born before referral to specialized centers. These are deaths that could have been avoidable with proper care.

Challenges Facing Care of Children with Congenital Heart Disease in Developing Countries. Even in the absence of crises, the diagnosis and management of congenital heart disease in developing regions face significant challenges when compared with developed countries. Late diagnosis, shortage of personnel and specialized facilities, and high complication rates are only a few of those challenges.[8–11] Such factors are only exaggerated in times of crises.

Preventable Morbidity and Mortality. The Syrian crisis is a clear example of preventable morbidity and mortality. The fact that 44 patients (37%) had failure to thrive at presentation reflects the poor nutritional support for refugees. Although children with heart disease are more likely to have nutritional deficiencies,[12] this becomes more pronounced for refugees with suboptimal living conditions,[13] and will inevitably increase their morbidity and complications of surgical interventions.[14] Moreover, many children with cyanotic heart disease presented with severe cyanosis (32%) with an oxygen saturation <70%, indicating delayed presentation to health care providers. Fifteen patients (13%) presented with severe complications of heart disease, again indicating late presentation.

Although mortality of congenital heart disease with optimum care is less than 5% in the current era, it may increase to more than 60% with no care as described in the 1950s as the natural history

of disease.[15] This poses a clear threat to children born in times of crises, where early diagnosis and proper management are hard to achieve. In our patient cohort, 14 of the 111 (13%) patients with congenital heart disease died by the end of follow-up period: Nine died waiting for surgery, which was postponed indefinitely pending funding. Four patients who otherwise would have needed a surgery were inoperable due to late presentation. Two died by the end of the follow-up and the other 2 are also expected to die prematurely. These unfortunate and indeed preventable deaths illustrate not only the dire need of more health care funding for Syrian refugees in Jordan, but also the shortage of adequate health care personnel and facilities to manage pediatric heart disease patients locally. Even when surgery was performed, after securing hard-to-find funding, patients had worse outcomes than the norm. Three patients died postoperatively as an inevitable result of late, complicated surgery.

High Incidence of Rare, Severe Disease. Notably, our data shows that relative to the small sample size, a relatively high number of patients (46%) were diagnosed with serious, cyanotic heart lesions compared with published data from the Middle East.[16,17] One particular example was the diagnosis of double-outlet right ventricle (DORV), a serious cyanotic heart lesion. DORV is the 12th most common congenital heart defect, and usually makes up 1% of all congenital heart defects, with an incidence of 0.03 to 0.1 per 1000 live births.[18] But in our study population where 111 patients had congenital heart disease, 17 (15%) were diagnosed with DORV, a much higher figure than what is reported in the literature.

Many Less Severe Lesions Still Undiagnosed. As previously described, we divided patients into 4 categories, based on their need for follow-up and intervention. This categorization correlates with the severity of their disease. The majority of patients (71%) fell in categories C and D. To explain the high percentage of severe disease in our patient population, a few things come to mind: Patients with simpler lesions usually have fewer, less severe symptoms and might not be eligible for priority referral to tertiary health care facilities. Also, for patients born in Syria, simpler lesions could have been more easily and properly repaired before patients' refuge to Jordan, further skewing our data toward severe disease. The drawback to this is that many patients with less severe lesions were not referred for proper evaluation and/or remain undiagnosed, and are at a risk for complications, morbidity, and mortality in the future.

Endless Wait for Lifesaving Intervention. The number of surgical and catheterization procedures indicated was 132; however, only 65 (49%) were actually performed. Of those, 37 were catheterization procedures. The lower number of surgeries versus catheterizations performed demonstrates a number of points, the most important of which is the high cost of surgery for these patients and the lack of funding. It also displays the relative shortage in the field of pediatric heart surgery in Jordan. This shortage is a significant challenge that has led health providers to look for solutions such as inviting visiting surgical teams from developed countries to visit every few months and perform surgeries for scheduled patients. Sending patients abroad to get treated was another approach. The high cost and logistical issues with both visiting teams and overseas transport have made such solutions impossible to apply to all patients.

We also note that patients who are still waiting for surgical interventions have been doing so for a very long time, much longer than for patients who ended up receiving surgical intervention. This is explained by the fact that patients with complex lesions are more expensive to treat, which makes it harder to secure their funds. Additionally, both local and visiting teams are more likely to select patients with simpler lesions for treatment, leaving patients with more complex lesions waiting indefinitely.

CONCLUSION

This study brings the problem of heart disease in Syrian refugee children into focus. These victims of the crisis are faced with the issues of late presentation, late referral, and delayed diagnosis. Even when diagnosed, they face other challenges due to unavailability of funds, shortage of specialized centers and personnel, and a higher risk for complications due to long waiting time.

Although most health needs of refugee children are those of disease prevention and primary health care, this study demonstrated that children with complex and life-threatening conditions are suffering from preventable morbidity and mortality. There is a dire need for organized efforts to properly diagnose and manage such children in these times of crisis.

Annals of Global Health, VOL. 82, NO. 2, 2016
March–April 2016: 300–306

REFERENCES

1. UNHCR: Syria Regional Refugee Response; July 30, 2014. Available at: http://data.unhcr.org/syrianrefugees/regional.php. Accessed February 17, 2015.
2. Inter-agency Regional Response for Syrian Refugees: Health and Nutrition Bulletin, Iraq, Jordan and Lebanon. January - March 2013. http://data.unhcr.org/syrianrefugees/download.php?id=1935. Accessed February 17, 2015.
3. Murshidi MM, Qasem M, Hijjawi B, Jeriesat S, Eltom A. Syrian refugees and Jordan's health sector. Lancet 2013;382:206–7.
4. El-Khatib Z, Scales D, Vearey J, Forsberg BC. Syrian refugees, between rocky crisis in Syria and hard inaccessibility to healthcare services in Lebanon and Jordan. Confl Health 2013;7:18.
5. Hoffman JIE, Kaplan S. The incidence of congenital heart disease. J Am Coll Cardiol 2002;39:1890–900.
6. Van der Linde D, Konings EEM, Slager MA, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. J Am Coll Cardiol 2011;58:2241–7.
7. Birth Rate, Crude (per 1,000 People). Data. World Bank. Available at: http://data.worldbank.org/indicator/SP.DYN.CBRT.IN. Accessed February 17, 2015.
8. Mocumbi AO, Lameira E, Yaksh A, Ferreira MB, Sidi D. Challenges on the management of congenital heart disease in developing countries. Int J Cardiol 2011;148:285–8.
9. Bode-Thomas F. Challenges in the management of congenital heart disease in developing countries. Congenital Heart Disease-Selected Aspects. Available at: http://cdn.intechopen.com/pdfs-wm/26663.pdf. Accessed February 17, 2015.
10. Hoffman JIE. Global burden of congenital heart disease. Cardiovasc J Afr 2013;24:141–5.
11. Jonas RA. Congenital heart surgery in developing countries. Semin Thorac Cardiovasc Surg Pediatr Card Surg Annu 2008;11:3–6.
12. da Silva VM, de Oliveira Lopes MV, de Araujo TL. Growth and nutritional status of children with congenital heart disease. J CardiovascNurs 2007;22:390–6.
13. Bilukha OO, Jayasekaran D, Burton A, et al. Nutritional status of women and child refugees from Syria–Jordan, April–May 2014. MMWR Morb Mortal Wkly Rep 2014;63:638–9.
14. Radman M, Mack R, Barnoya J, et al. The effect of preoperative nutritional status on postoperative outcomes in children undergoing surgery for congenital heart defects in San Francisco (UCSF) and Guatemala City (UNICAR). J Thorac Cardiovasc Surg 2014;147:442–50.
15. Adams F. Congenital heart disease: comments regarding incidence and natural history. Calif Med 1959;90:213–6.
16. Chehab G, Bittar Z. Cumulative incidence and distribution of congenital heart diseases in newborns in Beirut and its southern suburb (1999-2002). J Med Liban 2004;52:121–5.
17. Al-Mesned A, Al Akhfash AA, Sayed M. Incidence of severe congenital heart disease at the province of Al-Qassim, Saudi Arabia. Congenit Heart Dis 2012;7:277–82.
18. Corno AF. Double outlet right ventricle. In: Corno AF, ed. Congenital Heart Defects: Decision Making for Cardiac Surgery, Vol. 2. Heidelberg, Germany: Springer; 2004.