



# The role of diaspora and non-governmental organization in helping Sudanese children with congenital heart diseases: 6 years' paediatric cardiac surgery camps experience

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**Background:** Sudan one of the largest countries in Africa. In recent survey by Sudan Ministry of Health, congenital heart disease (CHD) was found to be one of the top eight diseases that lead to death of children in Sudan. The cost of surgical operation, follow up and diagnosis are expensive and this may result some children present with complications. The aim of this study is to assess the role of diaspora and non-governmental organization (NGO) in helping Sudanese children with CHD.

**Methods:** We assess the 6 years' experience in charitable initiative established by Sudanese consultant pediatric intensivist and cardiologist working in Doha, Qatar in partnership with NGO in Gulf countries and Sudan. Examples of these organizations were Patient Helping Fund (PHF) the largest medical charity in Sudan, Eid Althani charity association in Qatar with collaboration of the Federal Ministry of Health (FMH), Ministry of Health in Khartoum and Gazira states. We established the program of providing suitable care for in need children.

**Result:** A total of 104 out of the 222 complex defects were considered for surgery, 118 underwent cardiac catheter interventions. The 30-days post-operative mortality was 14/222 (6.3%). The most essential post-surgical complications were postpericardiotomy syndrome, bleeding, and sepsis. Malnutrition poor socioeconomic status is significant factors negatively impact the outcomes. All surviving patients (n=208) remain in good clinical condition, and most are asymptomatic without any medications.

**Conclusions:** The collaboration of Sudanese pediatrician living outside Sudan with local and international NGOs can significantly improve child health in Sudan.

**Keywords:** Congenital heart disease (CHD); children; Sudan; non-governmental organizations (NGOs)

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## Introduction

Congenital heart diseases (CHD) is one of the top eight diseases that lead to the death of children in Sudan as identified by the Ministry of Health in Khartoum state (1). Worldwide the incidence of CHD is about 8 in every 1,000 live born babies. Significant geographical differences were found, for instance, in Asia, the prevalence is 9.3 per 1,000, Europe 8.2 per 1,000 and North America 6.9 per 1,000 live births (2). In Sudan, some article reported that the prevalence of CHD is 0.2% (2 per 1,000 live births) in pediatric age group and about 1.5% of all deliveries diagnosed as cardiomyopathy (3). Although the prevalence is higher than the worldwide prevalence of CHD, the resources to diagnose and manage this group of ill children is so much lacking behind. There are three cardiac medical centers in Sudan. Two located in Khartoum state and the third is in Wad Madani 180 Kilometers south of Khartoum (4-8). Most of the trained physicians and surgeons are specialized for adults' cardiac diseases. The known waiting number of children to get the proper cardiac surgery or catheter intervention is more than 1,500 children. The most challenging factors in performing cardiac operation in developing countries like Sudan are the unavailability of the well-trained medical staff and the limited necessary technical resources. This likely because the priority in the health authority strategic plans is to treat endemic disease (5-8).

Currently, there is only one well-trained pediatric cardiac surgeon in Sudan, not more than four well-trained pediatric cardiac interventionists; no well-trained graduated respiratory therapist and no well-trained specialized pediatric ICU (PICU) nurses. In addition, the PICUs are considered to be low set up regarding equipment and advanced monitoring system. Other important factors that contribute to mortality and morbidity of children with CHD are comorbidities like severe malnutrition, recurrent protozoal infections, illiteracy and low socioeconomic status. The cultural and religious background of the family has an indispensable impact in the decision of seeking a cure for their CHD children (e.g., some of them believe that such malformations created by Allah (God) should be accepted as it is).

Unfortunately, due to late diagnosis and lack of facilities, late presentation of children is always associated with complications like Eisenmenger's syndrome or severe pulmonary hypertension that is beyond the capacities of Sudan cardiac centers to provide them the required intervention. About 10% of Down's syndrome children with CHD having Eisenmenger's syndrome at the time of presentation (4). The reported mortality following cardiac

surgery for CHD children is 8.3% in Sudan cardiac center. Two third of the surgical intervention performed by the local medical staff and one third by visiting team over 1 year (5-8).

## Methods

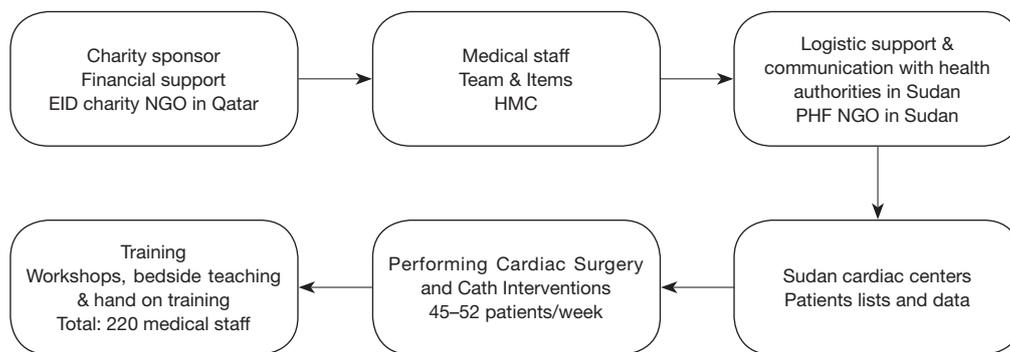
This initiative of helping Sudanese children with CHD was started in 2011 by some Sudanese doctors based in Doha, Qatar. This initiative was in response to the request made by the senior pediatric cardiologist in Ahmed Qasim cardiac center in Khartoum, calling for urgent help for sixty waiting children with CHD required immediate cardiac intervention. As a Sudanese pediatric intensivist and pediatric cardiologist in diaspora at Hamad Medical Corporation in Doha, Qatar we decided to move for help on a charity basis, our aim was to treat children with CHD by cardiac surgery or/and cardiac catheter interventions, to share our experience and transfer our knowledge to the local medical staff in Sudan. Also, to provide teaching and hand on training for the Sudanese medical and paramedics in the field of managing CHD children at all stages preoperative, intraoperative and postoperative. Stablishing steering committee by the diaspora physicians in Doha targeting to achieve these aims to improve the health system in Sudan and adequately reducing the mortality and morbidity of one the top eight killing diseases in children (*Figure 1*).

Coordination and partnership are bringing Patient Helping Fund (PHF) the most significant medical charity in Sudan, Eid Althani charity association in Qatar with the collaboration of the Federal Ministry of Health (FMH) in Sudan, Ministry of Health in Khartoum and Gazira states, we established the program of providing suitable care for in need children.

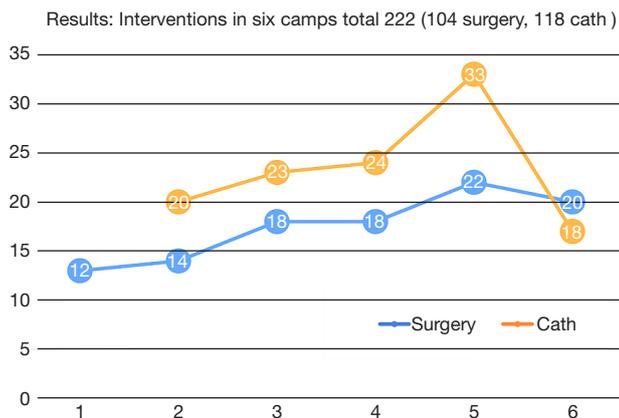
We studied the epidemiological, clinical, echocardiographic and surgical data from camps mission's summary, from the local physician's referrals and documents. The 30 days' post-operative outcomes within the available PICUs resources and capabilities were assessed.

## Results

A total of 104 out of the 222 complex defects were considered for surgery, 118 underwent cardiac catheter interventions (*Figure 2*). With increased number of medical team, more interventions performed mission after mission (*Figure 3*). The 30-days post-operative mortality was 14/222 (6.3%). The most important post-surgical complications were postpericardiotomy syndrome, bleeding, and sepsis. Malnutrition poor socioeconomic status is significant factors



**Figure 1** The chain of mission preparations showing steps taken by Sudanese pediatricians in Qatar to support and help Sudanese children with CHD. CHD, congenital heart disease; NGO, non-governmental organization; PHF, Patient Helping Fund; HMC, Hamad Medical Corporation .

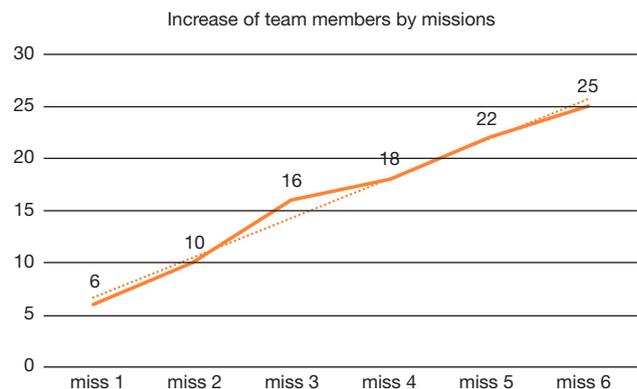


**Figure 2** It shows 6 years program (1–6 years, one mission per year), while the number in dot indicates the number of surgical or cardiac operations or catheter performed in that year.

negatively impact the outcomes (Figure 2). All surviving patients (n=208) remain in good clinical condition, and most are asymptomatic without any medications.

### Discussion

Organizing cardiac camps by diaspora physicians can do a lot in form of transfer of knowledge and skills across disciplines, build upon the local capacity. It provides relevant and life-changing interventions, and immediate changes leading to sustainable longer-term developments (9). It raises up the awareness of the health authorities about the importance of dealing with CHD children by adjusting the local facilities with the help of expertise that can be recruited through a partnership between diaspora, domestic and international



**Figure 3** With increased number of medical team, more interventions performed mission after mission. Of note the last local cardiac center has the lowest facilities lead to a drop in the total number of responses (miss stand for mission).

non-governmental organizations (NGOs). This may in part suggest at least one benefit gained from the emigration of doctors from sub-Saharan Africa (10). Although the 104 CHD children who underwent cardiac surgeries during a total of 36 working days over the six cardiac missions still the mortality rate (6.3%) is less than the reported mortality rate from Sudan cardiac centers (8.3%) (5-8). The most challenging factors in performing cardiac surgery in developing countries are the unavailability of the well-trained medical staff, limited necessary technical resources, and the absence of some rescue therapeutic measures namely inhaled nitric oxide and milrinone. The comorbidities of the endemic health problems like severe malnutrition, failure to thrive, severe nutritional anemia and chronic protozoal infections have a major adverse effect on the outcome following cardiac

surgery (6,7). The cultural beliefs and religious background cannot be ignored. The level of training and experience of the medical team is an essential factor to get the best outcomes in low set PICU. So, build up the medical team quantity and quality wise mission after mission (from 7 members in the first mission to 22 in the Six One). Sharing and transfer knowledge and experience with the local medical staff through companied teaching rounds workshops and other educational activities during camps improved the patients' outcomes. Some of the literature from Sudan reported that the prevalence of CHD in children is about 0.2% (2 per 1,000 live births) (3), which is low compared with the worldwide prevalence. This is most likely due to under-reporting of other cases that lived in areas where it is difficult to access any pediatric cardiac service.

## Conclusions

The partnership between diaspora physicians in one hand and local and international NGOs proved to raise the awareness of the high health authorities in Sudan to adjust their local facilities with some modifications to reduce the mortality of children with underline CHD. Our experience through the six camps showed that the outcomes dramatically improved with the increase in the number of the expert medical team. More training and exposure of the local staff have a positive impact in treating children with CHD through diagnostic and therapeutic interventions. Training and education of Sudanese medical staff during the charity cardiac missions and continuity of that by different workshops and courses is one of the fundamental requirements to help CHD pediatric population in Sudan.

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