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REVIEW ARTICLE

Paediatric cardiology programs in countries with limited resources: how to bridge the gap

Sulafa K.M. Ali *

University of Khartoum, Faculty of Medicine, Department of Paediatrics and Child Health, P.O. Box 102, Khartoum Erkaweit, Sudan

Department of Pediatric Cardiology, Sudan Heart Center, P.O. Box 11917, Khartoum Erkaweit, Sudan

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Abstract Establishing paediatric cardiology service in a country with limited resources like Sudan is a challenging task.

A paediatric cardiac team was formed then the services in different disciplines were gradually established. Echocardiography (echo) clinics were founded in tertiary and peripheral hospitals. Cardiac catheterization (cath) was established at the Sudan Heart Centre (SHC) in 2004 and over 400 procedures had been performed including interventional catheterization like pulmonary valve dilatation, patent ductus arteriosus and atrial septal defect device closure.

Congenital heart surgery started in 2001, currently 200 cases are done each year including closed procedures as well as open heart procedures for patients weighing more than 8 kg. Cardiology-cardiac surgery as well as adult congenital heart disease meetings were held and contributed positively to the services. The cardiology-cardiac surgery scientific club meeting was founded as a forum for academic discussions. A fellowship program was established in 2004 and included seven candidates trained in paediatric cardiology and intensive care. Two training courses had been established: congenital heart disease echo and paediatric electrocardiogram interpretation. Links with regional and international cardiac centres had important roles in consolidating our program.

* Address: University of Khartoum, Faculty of Medicine, Department of Paediatrics and Child Health, P.O. Box 102, Khartoum Erkaweit, Sudan. Tel.: +24 (918) 3232133/3232137; fax: +24 (918) 3232135. E-mail address: sulafakhalid2000@yahoo.com



Significant obstacles face our service due to the small number of trained personnel, high cost of procedures, the lack of regular supplies and lack of cardiac intensive care facilities for young infants.

Bridging the huge gap needs extensive official as well as non-governmental efforts, training more staff, supporting families and collaboration with regional and international centres.

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1. Introduction

Sudan is the heart of Africa, lying in its centre with an area approaching one million square miles. It has enormous economical resources however not yet efficiently utilized. Cardiology services in general were available only as part of general medical practice till 1960s when the first cardiac centre (Al Shaab) was established to deliver specialized cardiac services. Modern cardiology services with the introduction of echocardiography (echo) became available in late 1980s. A cardiac catheterization (cath) laboratory was established in Al Shaab hospital in the same period of time and was functioning only for few years. In 2000 two dedicated cardiac centres were established, namely Sudan Heart Centre (SHC) and Ahmed Gasim Heart Centre where facilities for echo, cath and open cardiac surgery became available for the first time in Sudan. Care for children with heart disease was delivered by paediatricians and adult cardiologist up to 2001.

1.1. Paediatric cardiology in Sudan

In 2001 paediatric cardiology was established and the number of cardiologists contributing increased over several years to ten. In 2004 the author established a Paediatric Cardiology Department at the SHC which included outpatient, inpatient, cardiac catheterization and paediatric cardiac intensive care. The pillars of paediatric cardiology program are early diagno-

sis, echo, cardiac cath, surgery and post operative care, training and research. Establishing a new program require working on all these aspects simultaneously.

2. Establishing a paediatric cardiology program

2.1. Step 1: Making a team

The program started at the SHC by establishing the first paediatric cardiology department and recruiting physicians (fellows, residents) to make the TEAM. Team work with our surgeon is vital to provide better care to patients. An important concept is not to blame each other and tolerate each other's 'tantrums'.

2.2. Step 2: Initiating and consolidating the services

2.2.1. Out patients

The main clinics at the SHC as well as satellite clinics in the main hospitals were established where large numbers of children were screened. The peripheral clinics were gradually supplied with good quality echo machines and eventually an echo clinic became available on daily basis in the main children's hospital.

We recorded the cases seen and established a mini-Database that enabled us to publish important papers about the frequency of the different congenital heart disease in Sudan, their

management and outcome (Sulafa and Karani, 2007), the high frequency of Ebstein disease (Sulafa and Nuha, 2006), the outcome of children with Down's syndrome, the clinical and echocardiographic features of patients with atrioventricular septal defects (Sulafa, 2009a,b) as well as reporting series of patients with noncompaction and tropical restrictive (endomyocardial fibrosis) types of cardiomyopathy (Sulafa, 2008a, 2009c).

We also started patient's counseling using heart diagrams and Parents' Information Pamphlets designed using simple local (Arabic) language including the diagnosis and treatment plans.

A dedicated clinic for rheumatic heart disease was established. Management protocols were produced using World Health Organization references.

2.2.2. Improving echo services

Echo manuals were provided to all our clinics containing reference values and stressing the need to perform standard echoes using segmental approach. Recording images was initially challenging but recently digital systems became available. Echo technicians are not yet fully utilized and we still depend on physicians.

2.2.3. In patient wards

The main paediatric cardiology ward lies in the children's hospital with referral to SHC only for surgery or cath. Clinical, CXR and ECG sessions with a rich clinical material facilitated teaching and training of residents and fellows. Protocols for management were made available in our ward as well as for residents and consultants elsewhere.

2.2.4. Cardiac catheterization for children

Cardiac cath for children was initially performed by adult cardiologist and included diagnostic and some interventions like pulmonary valve dilatation. Few cases of device closure of patent ductus arteriosus (PDA) and atrial septal defect (ASD) were done by a visiting cardiologist in 2003. In 2004 we established a dedicated paediatric cath program. Protocols for diagnostic and interventional procedures were set. We performed around 400 procedures, 25% of them were interventional including pulmonary valve dilatation PDA, ASD device closure and balloon atrial septostomy (Sulafa, 2008a,b) (Table 1). Initially we used the Amplatzer occluder device (AGA, USA) then we started to use another brand (Balmedic, China) with results as good as the Amplatzer device.

2.2.5. The cardiology-cardiac surgery meeting

The meeting was established in 2004. The cases selected from the outpatient clinic or catheterization lab were discussed with

the cardiac surgeon. Echoes and angiograms were presented to the surgeon. Discussions were documented in a folder that is kept as a reference.

2.2.6. Intensive care unit (ICU)

The common ICU at the SHC serves all adult medical and surgical cases as well as children. Till 2004 the post operative care for children was delivered by the surgical team. The surgical residents are often not familiar with the intensive care management of young infants. In 2004 we collaborated with the surgeon and introduced on call system that includes a paediatric specialists to cover at least the first post operative night in the ICU. The specialists were supervised by the first author and received multiple sessions on ICU management. A manual for Postoperative Management Protocols was made available in the ICU to be used by medical and nursing staff. Two young paediatric specialists were sent abroad for a fellowship program in paediatric cardiac intensive care. This system helped the surgical team and definitely contributed to lowering the weight for open heart surgery.

2.2.7. Congenital heart surgery

Congenital heart surgery started by closed procedures like coarctation repair, PDA ligation and Blalock –Taussig shunts (BTS) in 1980s. Open cardiac surgery started in 2000 by doing Tetralogy of Fallot (TOF), ventricular septal defect (VSD) and ASD repairs in patients more than 10 kg. Dedicated congenital heart surgeons became available in 2002 and started performing closed procedures in infants as small as 4 kg (PDA ligation, pulmonary artery bands (PAB) and BTS). Procedures expanded to include open heart surgery which is done for children weighing more than 8 kg. Procedures expanded to include atrioventricular septal defects (AVSD), complex ASDs and cavopulmonary connections. The first surgeon at the SHC was Dr. Z Karani (2002–2006) who performed 200 operations (Sulafa and Karani, 2007). Another surgeon, Dr. M. Ibrahim operates at Ahmed Gasim Cardiac Centre and joined SHC in 2006 is currently the only surgeon dedicated for congenital heart disease in Sudan.

2.2.8. Adult congenital heart disease meeting

Adults with CHD impose a significant burden on our service. This meeting was established in collaboration with our Adult Cardiologists. All adults with CHD were discussed in this meeting before proceeding to invasive investigations. The meeting had a significant role in improving patients' management and training of adult cardiology fellows.

Table 1 Interventional catheterization procedures done at the Sudan Heart Centre by the local staff from July 2004 to February 2010 and their outcome.

Procedure	No. (%)	Outcome (success/failure)	Complications	Follow up
PDA closure	40	40/0	Non	No residual shunt, no stenosis of left pulmonary artery or aorta
Pulmonary valve dilatation	22	17/5	Non	Pressure gradient abolished in 17, 3 Noonan syndrome and two young infants referred for surgery
Balloon atrial septostomy	12	10/2	Vascular injury (1)	Two failed vascular access (one with low birth weight)
Atrial septal defect closure	3	3/0	Non	Successful occlusion
Aortic valve dilatation	1	1/0	Non	Gradient dropped by 50%

2.3. Step 3: Training, academic activities and research

An informal fellowship program was initiated where fellows were trained in clinical skills, chest radiographs, ECG interpretation and echo skills. Periodic academic activities included topic reviews and journal clubs. One of our objectives was to join all paediatric cardiologists/fellows in town into a club meeting and that was initiated in 2006 (The paediatric cardiology/cardiac surgery Club Meeting). Two important courses were established: a paediatric ECG/arrhythmia interpretation course and a Congenital heart disease echo course. The courses were attended by a good number of candidates including echo technicians and physicians working outside Khartoum. Our fellows were encouraged to participate in research activities and contributed in all the paediatric conferences held in Khartoum in the last few years.

2.4. Step 4: Collaboration with regional and international organizations

The Children's Heart Foundation charity group from Memphis/USA led by Professor William Novick conducted four visits in 2003, 2004 and 2005 and performed 52 operations mostly for infants less than 8 kg. The vast experience of Professor Novick in the field of congenital heart surgery in developing countries is well established (Sulafa, 2008a,b).

Other similar teams contributed to establishment of a regional referral centre in Guatemala serving many countries in South America (Novick et al., 2005).

These programs are highly needed in our area and in our experience had contributed significantly to our program by training our ICU doctors and nurses. Dr. M.T. Numan from Hamad Medical Corporation-Qatar visited SHC three times and performed 50 interventional catheterizations. These visits had a vital role in consolidating our interventional program (Fig. 1).

2.5. Step 5: Combating the problems

Many obstacles face us when managing congenital heart disease in Sudan, the main problems are:



Figure 1 The cardiac catheterization team from Hamad Medical Corporation, Doha, Qatar led by Dr. M.T. Numan (first on the left) and Mr. Abdullah Ashkinani (second to the left) with the SHC team: (standing in the centre (front) is the author).

2.5.1. Technical problems

- (1) The small numbers of trained staff including physicians, nurses (especially in intensive care and cath lab) as well as technicians in echo and cath lab. Training locally and collaboration with regional centres can help to solve this problem.
- (2) Lack of specialized paediatric intensive care units: because of this problem we limited our interventional catheterization as well as open heart surgery to older infants (weighing more than 8 kg).
- (3) Lack of regular supplies in the cath lab: the supplies for children are not regular because of the small numbers of patients and the high cost of catheters. We often had to use adult sheath (11 cm – 5 and 6 French) for infants and young children. Special paediatric catheters mini puncture needles and wires not commonly used by adults are often lacking. Certain political issues often interfere with supply availability. It is considered routine that we re-sterilize catheters and needles and re-use them. Interestingly we did not practically face any problems while using these catheters, findings similarly reported (Kumar and Shrivastava, 2008, Larrazabal et al., 2007). We routinely screen patients for hepatitis and HIV and discard equipment used for positive patients.

2.5.2. Financial problems

Cardiac procedures are only partly insured therefore patients pay up to 3000 US dollars for surgery and interventional catheterization procedures. Patient-support groups are activated but their role remains limited. This affects not only the patient management but also the learning curves for the different procedures as the numbers performed are limited.

2.5.3. How can we bridge the gap?

- Including cardiac procedures in medical insurance which should involve ideally all paediatric patients.
- Increasing the numbers of trained cardiologists in the main cities outside the capital.
- Increasing the numbers of trained personnel especially congenital heart surgeons and ICU nurses. This can be accomplished by regional and international collaboration with peer cardiac centres.
- Gradual introduction of newer technologies like 3 dimensional echo, cardiac MRI/CT.
- Introduction of important cath interventions like PDA and coarctation stenting
- Improving neonatal screening and fetal echo for early detection
- Improving neonatal and early infant open heart surgery.

In conclusion a basic paediatric cardiac program is found, we need to work hard to consolidate this program and bridge the huge gap in this service.

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