

# Optimal paediatric cardiac services in South Africa – what do we need?

Statement of the Paediatric Cardiac Society of South Africa

E.G.M. Hoosen\*, A.M. Cilliers#, C.T. Hugo-Hamman+,  
S.C. Brown\$, J.R. Harrisberg†, F.F. Takawira§,  
K. Govendrageloo†, J. Lawrenson‡ and J. Hewitson\*\*

\* Paediatric Cardiology, Inkosi Albert Luthuli Central Hospital, University of KwaZulu-Natal, Durban

# Division of Paediatric Cardiology, C.H. Baragwanath Hospital, University of Witwatersrand, Johannesburg

† Paediatric cardiologist, Constantiaberg Medi Clinic and lecturer, University of Stellenbosch, Cape Town

‡ Department of Paediatric Cardiology, Universitas Academic Hospital University of the Free State, Bloemfontein

§ Paediatric cardiologist, Sunninghill Hospital, Johannesburg

§ Department of Paediatric Cardiology, Steve Biko Academic Hospital and University of Pretoria

‡ Paediatric Cardiology Services of the Western Cape, Red Cross Children's Hospital and Tygerberg Hospitals University of Cape Town and Stellenbosch University, Cape Town

\*\*Cardiothoracic surgeon: Red Cross Children's Hospital, University of Cape Town

## Address for correspondence:

Dr E.G.M. Hoosen  
Paediatric Cardiology  
Inkosi Albert Luthuli Central Hospital  
800 Bellair Road  
Durban  
4001  
South Africa

## Email:

ebrahimhoo@ialch.co.za

## INTRODUCTION

The audit of paediatric cardiac services accompanying this statement highlights some of the concerns and issues regarding the state of services for children with heart disease in South Africa. While a number of the issues apply to all aspects of health care in the country, it is clear that the needs of children with congenital heart disease are not being adequately met, and, if this situation is to be salvaged, a vision of how this service should be developed and structured is required.

## ABSTRACT

Most children with congenital heart disease have a good outcome if treated appropriately, however the majority of children with heart disease in South Africa do not receive appropriate care. This is related to serious deficiencies in the mechanisms and training for early detection as well as a major shortage of skilled personnel to care for these children at all levels. Most public sector hospitals are unable to cope with the number of patients requiring surgery, mainly due to inadequate theatre time allocation and intensive care facilities. Key interventions to address these deficiencies include:

1. Strategies to improve both the training and the retention of all professionals involved in the care of congenital heart disease.
2. Programmes to increase awareness of both congenital and acquired heart disease in children among health care personnel.
3. Ensuring appropriate infrastructure and equipment designed for children with congenital heart disease are available.
4. Development of congenital heart surgery as an independent subspecialty with dedicated resources and personnel.
5. Dedicated intensive care facilities for paediatric heart surgery.

In addition, development of appropriate patterns of referral, stimulation of research and positive private-public partnerships are all necessary to ensure that appropriate care is delivered. SAHeart 2010; 7:10-16

Providing comprehensive care for children with heart disease requires an integrated team of inter-dependent health practitioners. The team members include cardiologists, cardiothoracic surgeons, anaesthetists, intensivists, cardiac technologists, perfusionists, nurses, social workers and physiotherapists. These team members provide special, very specific skills in dealing with this group of patients. The care of these patients often needs to continue into adulthood and adult cardiologists with the necessary training to care for congenital heart disease in adults are essential. Weaknesses or a deficiency at any level, or the inability of the team to function together seamlessly, seriously compromises patient care.

It is clear from the accompanying audit that the paediatric cardiac services within most of the public sector are unable to meet the needs of patients presenting to them, despite the fact that there is under diagnosis, with a large proportion of patients, particularly neonates and infants, not being referred for appropriate therapy. The burden of patients is likely to increase with the gradual improvement in primary and secondary health care. Poor working environments in some of the public service sector hospitals adds to the frustrations of health care workers resulting in an endless cycle of training and loss of all staff categories to the lure of better working environments and more lucrative job offers elsewhere, which further compromises the services.

It is sometimes questioned whether paediatric cardiac services should be a priority in South Africa, when HIV, diarrhoeal disease and respiratory tract infections have been shown to be the most common causes of under 5-mortality. Medical Research Council (MRC) statistics show cardiac abnormalities to be responsible for 1.2 percent of under 5 mortality, the 8th most important cause of mortality in childhood in this country.<sup>(1)</sup> The accuracy of this figure can be questioned, since the proportion of children with undiagnosed congenital heart disease that die labeled as respiratory tract infection, gastroenteritis or neonatal sepsis is unknown. It is not uncommon for the patient with congenital heart disease to manifest for the first time with one of these diagnoses.

Of great importance is the fact that up to 85% of children with congenital heart disease, if managed appropriately, can reach adulthood.<sup>(2)</sup> If left undiagnosed and untreated, congenital heart disease places a significant, but largely unrecognised and unquantified burden on the health care system in South Africa. It is likely that recurrent admissions and clinic visits for management of complications related to untreated congenital heart disease could be far more costly than if the patient received definitive and prompt treatment at the initial presentation. This scenario plays out everyday in our tertiary care institutions where delayed management due to long cardiothoracic surgery waiting lists results in costly prolonged hospital stays and recurrent admissions. What is even more difficult to quantify is the physical and mental suffering of patients and their families as well as the economic burden that frequent hospital visits and absenteeism places on them.

Interventional cardiac catheterisation has to some extent been able to alleviate the paediatric cardiac surgical burden. The spectrum of patients suitable for percutaneous cardiac interventional procedures has increased significantly over the last decade. The major advantage of these new procedures is that the hospital stay is shortened, scarce intensive care unit (ICU) services are not usually required, and some of the procedures can be performed under conscious sedation without the need for an anaesthetist.

As the spectrum of cases treated in the catheterisation theatre grows and the demand for interventional procedures increases, the international trend towards further specialisation in interventional paediatric cardiologists will become necessary.

The last discussion within South Africa addressing the needs of a paediatric cardiac service on a national level was reported in 2002 in the document on "Modernisation of Paediatric Cardiac Services".<sup>(3)</sup> The primary challenges outlined in this document related to inadequate surgical output, staff attrition, poor transport infrastructure and lack of adequate equipment all of which remain as critical issues seven years later. Concern was expressed within the 2002 report regarding the inadequate number of operations done annually with an estimated total of 1380 operations countrywide. As the current audit shows, there has been no improvement in surgical output despite an increasing population size.

Internationally, the rapid technological developments in diagnosis and management of congenital heart disease have been associated with major changes in the function of paediatric cardiac centres. The impetus for some of these changes can be ascribed to public outcry and demand following recognition of substandard services and facilities. The most infamous account of poor paediatric services was reflected in the Bristol Inquiry,<sup>(4)</sup> where the postoperative paediatric cardiac surgical mortality at the Bristol Infirmary was found to be twice the normal of acceptable standard documented at any other unit in the UK.

The following were among the important findings of the enquiry:

- The cardiologists and surgeons were in separate hospitals.
- The cardiologists were understaffed and could not participate effectively in the surgery and intensive care of their patients.

- The prevailing national shortage in nurses trained in caring for children was reflected in Bristol.
- The surgeons operated on adults and children; and the children were nursed alongside adults in a mixed intensive care unit.
- While there was an effective child-centered approach to care at the Children's Hospital, this was not so in the Bristol Royal Infirmary where open heart surgery was carried out.

In addition to the Bristol Inquiry Report, several other key recommendations from the United Kingdom,<sup>(5)</sup> United States<sup>(6)</sup> and Europe<sup>(7)</sup> regarding the care for children with heart disease have been published in recent years reflecting the need for institutional changes in the current era.

It is with this background that the recommendations for South African paediatric cardiac services are made with the understanding that:

- The recommendations are considered "best practice" by the majority of the paediatric cardiac community in the country. They are not intended to be prescriptive and acknowledge the varied circumstances and needs within each of the cardiac centres.
- Change will take time. Although the recommendations cannot be implemented overnight, the planning thereof should take place consistently and within realistic time frames.
- Change can only be brought about if all stakeholders including departmental heads and hospital administrators acknowledge shortcomings in paediatric cardiac services and are prepared to address them.

### **RECOMMENDATIONS FOR PAEDIATRIC CARDIAC SERVICES IN SOUTH AFRICA**

The recommendations cover the following areas:

- Structure of paediatric cardiac services;
- Infrastructure and equipment;
- Human resources and training; and
- Other important considerations.

A summary of the core human resource and facilities required for a paediatric cardiac service is shown in Table I.

#### **Structure of paediatric cardiac services**

Comprehensive paediatric cardiac services should be offered at referral units with good diagnostic and interventional cardiac services. Such services should include echocardiography, diagnostic and interventional cardiac catheterisation and cardiac surgical facilities.

As alluded to previously, a close relationship is required between the various disciplines of paediatric cardiology viz. medical, surgical, anaesthesiology and nursing components which may be more effective working together within a single paediatric cardiac unit under independent management.

Paediatric cardiac or congenital heart surgery, in particular, is likely to be far more effective if allowed to function separately from the mainstream cardiothoracic surgical units where the focus is generally directed away from the needs of children in terms of resource development and the allocation of budget, theatre time and intensive care beds. This separation of services is in line with current international trends and is the only way to ensure the continued growth and development of paediatric cardiac surgery.

#### **Regionalisation of services**

There may be advantages to regionalisation of certain services that are complex, require additional expertise and equipment or where certain services are particularly well developed and would improve outcomes if performed centrally. These specialised services could include cardiac transplantation, management of hypoplastic left heart syndrome and other complex cardiac conditions. The proviso to the adoption of these regionalised services should be that all patients, irrespective of their geographical position, would have equal access to the service. Transport for parents, and where necessary, assistance with the temporary relocation of the family or family members to the specialised center would have to be provided

#### **Infrastructure and equipment**

In addition to inpatient and outpatient facilities, basic infrastructure includes paediatric cardiac theatres, cardiac catheterisation laboratory and intensive care all of which should be in close proximity to each other to facilitate easy transfer of patients from one to the other.

**TABLE I:** Minimum personnel and facilities requirements for 250 paediatric cardiac operations performed annually

Personnel	Number	Comments
Paediatric cardiologists	6-12	Ideally : One per 0.5 million population
Paediatric cardiac surgeons	2 - 3	
Paediatric cardiac anaesthetists	2-3	
Paediatric cardiac technologists	3	
Cardiac perfusionists	3	
Facilities		
Biplane cath lab		Equipped for care of neonates and infants
Echocardiography	2 units	Should include facilities for BSU studies as well as transoesophageal studies
Perioperative intensive care	6 -8 beds	Nurse: patient ratio 1:1
Perioperative high care	2-4	Nurse: patient ratio 1:2
Perioperative ward beds	10-12	Refers to perioperative beds only. Additional beds are required for admission for other indications and percutaneous interventions.
ECMO and ventricular assist device		Require additional personnel for these services
CT angiography and cardiac MRI		Additional staff required

ECMO: extracorporeal membranous oxygenation; Cath Lab: cardiac catheterisation laboratory, CT: computed tomography, MRI: magnetic resonance imaging

Adapted from:

1. American Academy of Paediatrics: Guidelines for paediatric cardiovascular centers paediatrics 2002; vol. 109 No.3.

2. EACTS Congenital heart disease committee: Optimal structure of a congenital heart surgery department in Europe. European Journal of Cardiothoracic Surgery 24(2003) 343-351.

3. Multiple authors. Fifth report on the provision of services for patients with heart disease. (United Kingdom) Heart 2002;88 (suppl III): iii 1-iii59.

### Cardiac catheterisation laboratory

Biplane fluoroscopy facilities should be a standard feature in the paediatric cardiology catheterisation theatre. Consideration for hybrid procedures which are performed together by the paediatric cardiac surgeon and the paediatric cardiac interventionalist in a specially designed theatre should be taken into account when designing or upgrading facilities. Age appropriate resuscitation equipment and temperature control for younger children should be compulsory and all theatre staff should be well trained in the care of children.

### Intensive care

The development of appropriate paediatric cardiac intensive care units that specialise in the care of cardiac patients needing post-operative management is an essential part of paediatric cardiac services and contributes significantly to outcomes. Staffing with paediatric cardiac intensivists and an appropriate nurse to patient ratio should be aimed for. A lesser alternative is the allocation of cardiac beds within a general paediatric intensive care to post operative patients. The beds should be separated from other non-surgical patients to prevent transmission of nosocomial infections. This care should be coordinated by a single director.

The European guidelines consider six to eight paediatric cardiac intensive care beds as appropriate for every 250 operations performed. Specialised equipment such as nitric oxide ventilators, ventricular assist devices, and ECMO (extracorporeal membrane oxygenation) should be available for the management of difficult postoperative cardiac cases. Important life saving inotropic agents such Milrinone and Noradrenaline should be mandatory in any cardiac intensive care. Unfortunately, both medications remain unregistered for general use in South Africa. A laborious administrative procedure to obtain Medicines Control Council approval is required for every single use. Major efforts to encourage pharmaceutical companies to take the necessary steps and obtain registration for these less financially rewarding drugs should be encouraged.

### Echocardiography

Echocardiography is a fundamental diagnostic modality of any paediatric cardiac service which should have dedicated paediatric echocardiographic laboratories with basic equipment including transoesophageal transducers and mobile units that can be used for the entire spectrum of the paediatric population. In addition

to the minimum equipment requirements outlined in the "South African guidelines for paediatric echocardiography",<sup>(8)</sup> it is essential that services invest in newer technologies which include tissue Doppler imaging and 3D echocardiography. Paediatric cardiac units providing transoesophageal support in theatre or in the cardiac catheterisation laboratory should have at least two echocardiography machines available.

### Human resources

The greatest obstacle to appropriate paediatric cardiac services remains a lack of appropriately trained medical personnel.

### Nursing

A continuous nursing staff shortage prevails. No province has been able to fill available nursing posts resulting in 36.3 % vacant posts within the public service during 2007.<sup>(9)</sup> The intensive care sector is also seriously affected by a nationwide shortage of neonatal and paediatric nursing staff with some provinces being more severely affected than others.<sup>(10)</sup> These shortages severely limit paediatric cardiac services as staff require skills different to those required for adult cardiac or a general paediatric intensive care. An ideal service would include specially trained core nursing staff dedicated to care for patients in a paediatric cardiac intensive care and that are not rotated through other paediatric or medical services. Remuneration should be in accordance with the high level of skill and experience required. Ideally, paediatric cardiac intensive care nursing should be recognised as a separate nursing qualification.

Similarly, nursing sisters working in a pediatric cardiac catheterisation laboratory setting, have unique skills and should be recognised and appropriately remunerated.

A 1:1 nurse: patient ratio is essential within an intensive care with a ratio of 1:2 acceptable for a high care setting.

### Allied staff

Appropriately trained perfusionists play an integral part in the successful outcome of congenital heart surgery. Cardiopulmonary bypass for children is more complex than that for adults and requires additional training and expertise.<sup>(11)</sup> Perfusionists doing both adult and paediatric cases should perform a minimum accepted number of congenital cases annually to maintain a safe level of

practice. They should also ensure that they continue their medical education, keep up with new advances and adopt an evidenced based approach to cardiopulmonary perfusion techniques.<sup>(12)</sup>

Cardiac technologists provide essential services in areas such as the cardiac catheterisation laboratory, non-invasive electrophysiology, pacemaker implantation and follow up. Some centres provide training in echocardiography for technologists who are then able to alleviate a substantial part of the paediatric cardiologist's workload. A good team of appropriately trained and supervised technologists can substantially improve service outputs in centres that are understaffed by cardiologists. Urgent attention should be given to training technologists for this purpose.

### Paediatric cardiologists

The serious shortage of paediatric cardiologists needs urgent attention. Insufficient numbers are being trained to cater for the South Africa's needs and to counter the constant losses to emigration and the private sector. Recognition must be given to the fact that the training period for paediatric cardiology is three years compared to two years in other paediatric subspecialities. The longer training period is essential because of the various facets in which training is required viz. echocardiography and cardiac catheterisation which itself has two arms viz. diagnostic and interventional. The continuous broadening of paediatric cardiology into other subspecialties e.g. therapeutic interventional, foetal cardiology, electrophysiology, noninvasive imaging and adult congenital heart disease has necessitated further sub specialisation within paediatric cardiology.<sup>(5)</sup> Additional pressure is also placed on paediatric cardiologists, particularly in the public sector hospitals with university attachments, who have an additional teaching commitment to paediatric undergraduate and postgraduate programmes, and a requirement to produce research.

### Paediatric cardiac surgeons

The handful of paediatric cardiac surgeons in the country is an exceptionally important resource for paediatric cardiac services. Congenital heart surgery is technically very challenging and takes many years to develop the necessary expertise and skills to operate on the full range of congenital heart defects successfully. Training opportunities within South Africa are limited by the small number of qualified trainers and also the relatively small number of opera-

tions performed annually. It becomes essential for most paediatric cardiac surgical trainees to spend time abroad. A further major problem within the state sector is lack of appropriate career pathing and remuneration for paediatric heart surgeons. Many surgeons remain in positions which are not commensurate with their skills and are not adequately remunerated. The reorganisation of paediatric cardiology and congenital heart surgery into more cohesive, independent units may be one way of overcoming this problem.

#### Anaesthetic services

There is a general shortage of anaesthetists within the public sector that have appropriate skills to manage neonates and infants undergoing cardiac surgery. These shortcomings are likely to further compromise paediatric cardiac services unless specific measures are taken to train and retain paediatric cardiac anaesthetists.

#### Paediatric cardiac intensivists

Successful paediatric cardiac intensive care services require a multidisciplinary approach with contributions from paediatric cardiology, paediatric intensive care and anaesthetics. The need for specifically trained paediatric cardiac intensivists to deal with all aspects of post operative paediatric heart surgery is emerging and training programmes have been created in other overseas centres. There is a worldwide shortage of paediatric cardiac intensivists,<sup>(13)</sup> however, no programme exists within South Africa for the development of this specialisation. It is essential that, in our pursuit of international standards of care, development in this field becomes a priority.

#### Other important considerations

Ultimately, patient outcomes and the improvement of quality of care of children born with heart disease depends on a number of factors which include "early patient referral, definitive anatomic and physiologic diagnosis and optimal preoperative and post-operative care" which in turn rely heavily on appropriate facilities and human resources. Additional important factors are an adequate patient turnover to maintain skills, use of modern information technology and participation in a regional network of health care providers.<sup>(6)</sup> The high prevalence of HIV infection as well as the high continued prevalence of rheumatic heart disease are additional factors that impact on paediatric cardiac services.

#### Patient referrals

Appropriate and early referral of patients is a concern expressed by most paediatric cardiac centres, with only a small fraction of patients being referred timely for treatment. While factors such as poor infrastructure and properly trained personnel at the various referral centres may contribute, the most significant factor appears to be lack of awareness of the presenting features of cardiac disease in neonates, infants and children. An awareness programme needs to be developed within the various nursing colleges, medical schools, and also by continuing professional development initiatives.

Another problematic area is the national shortage of trained paediatric cardiologists who are required to sift out the patients needing further cardiac intervention from the mass of referrals which may or may not be appropriate. A third restricting factor in the referral arena is the limited number of intensive and high care beds available to the paediatric cardiac centres that are tasked with further management of these patients.

#### Adequate patient volumes

The retention of adequate patient turnover volumes has been identified as one important factor in improving surgical outcomes by ensuring that necessary skills are maintained and enhanced. The European guidelines suggest that each cardiac centre should undertake 250 operations per year, 100 of which should be in the neonatal or infant age range to maintain adequate skills. The number necessary for an individual surgeon to optimise their expertise is, according to these guidelines, 126 operations annually.<sup>(7)</sup>

The population size served by each of the public sector paediatric cardiac units in South Africa indicates that these minimum targets can be exceeded without difficulty if all efforts are made to optimise care.

It is, however, accepted that smaller units can and do produce consistent and excellent results, and patient volumes are only one factor determining outcome.<sup>(6)</sup> It is essential that all units monitor surgical outcomes and quality of care and develop mechanisms to improve them.

### Private-public partnerships and philanthropy

As already occurs within some units, a good relationship and strong interactions between the public and private sectors of the paediatric cardiac services in the country has the potential to enhance the care of children in both sectors of the population. This includes cross coverage of units with utilisation of skills from both sectors as well as joint academic activities.

Additionally, the Walter Sisulu Paediatric Cardiac Centre is a highly successful initiative able to provide paediatric cardiac services in a private setting to an increasing number of patients who are unable to afford private care.

Other initiatives to improve the care of children with cardiac disease include the Boikanyo Foundation which assists in increasing the surgical output at a public hospital (Johannesburg General) by raising additional funds for human resources and consumables and The Children's Hospital Trust that has funded the replacement of outdated equipment at the Red Cross Children's Hospital in Cape Town.

While such initiatives do not absolve the state of their responsibility to patient care, they have and continue to play an important role in improving care for all children with heart disease in South Africa.

### RESEARCH

There is an enormous need and potential for medical research in children with cardiac disease in South Africa. This applies not only to congenital but to acquired heart disease as well; specifically rheumatic heart disease and HIV associated cardiac disease. The high service loads and critical lack of staff significantly impact on the ability of units to produce research. Specific initiatives to stimulate research in this population are essential.

### CONCLUSION

Paediatric cardiac services represent a highly specialised but essential service for a patient group with potentially good outcomes. Successful outcomes for these patients can only consistently occur if attention is paid to every aspect of their care. A commitment is needed at all levels, from national to departmental, to ensure that these services are delivered.

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