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Guest editorial

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Paediatric cardiology in South Africa 2016: Quo vadis?



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New drugs and modern interventional strategies have markedly changed the face of paediatric cardiology in recent years. Advances in dealing with childhood cardiac disease have significantly improved outcomes. As a matter of fact, if properly managed, more than 85% of children with congenital heart disease (CHD) can reach adulthood.⁽¹⁾ It is also important to recognise that some of these are preventable and early recognition may markedly alter the course of disease and thus ultimately, the outcome. The main aim of the World Health Organisation's millennium development goal (MDG) 4 is to reduce the under 5 childhood mortality rate and the world heart federation has shown that not giving attention to cardiovascular disease may undermine all MDGs (www.worldheart.org).

The incidence of CHD is remarkably constant worldwide, ranging from 8 - 12 per 1 000 live births. However, due to high fertility rates, developing countries have a higher burden of disease per capita (up to 1%).⁽²⁾ CHD is by far the most common genetic related birth defect and more common than neural tube defects, Down syndrome and haemoglobinopathies added together.⁽³⁾ Little is published regarding the incidence of CHD in Africa, but statistically a large population of underserved children with CHD exist and studies have demonstrated the burden of CHD in Africa.⁽⁴⁻⁶⁾

In South Africa, statistics published by the Medical Research Council (2010) indicate cardiac abnormalities to be responsible for at least 1.2% of childhood deaths under the age of 5. This represents an underestimation of the true burden since a notable proportion of deaths due to infantile cardiac disease, remain either undiagnosed or hidden and is often mislabelled as unexplained respiratory tract infections, neonatal sepsis or neonatal respiratory distress syndrome. Acquired heart diseases, such as rheumatic fever, remain a problem with prevalence rates in recent South African studies varying from 5 - 22/1 000.⁽⁷⁻⁹⁾ Other conditions such as bicuspid aortic valve, pericardial and myocardial diseases may also develop over time and add to the burden of paediatric cardiac disease.

CHALLENGES IN SOUTH AFRICA

Under the auspices of the Paediatric cardiac Society of South Africa (PCSSA) a survey was carried out in 2006 which indicated that less than 40% of children with CHD are receiving the care they should be getting.⁽¹⁰⁾ A recent survey (unpublished) showed that four provinces, similar to the 2006 survey, still have no dedicated paediatric cardiology services – Limpopo, Mpumalanga, North West and the Northern Cape. The effects of these are emphasised by a simple mathematical model which showed that only 30 of 114 predicted cases of simple

transposition of the great vessels were operated on in South Africa in 2006. The survey also pointed out that only 1 370 of the expected 4 000 patients per annum requiring open heart surgery (based on demographic studies) were operated on.⁽¹⁰⁾ An informal survey in 2012 showed that the number of surgical cases increased to only 1 537 in the face of a growing population. These findings point to serious deficiencies in not only the detection, but also the management of severe congenital heart disease.

WHAT ARE THE REASONS?

The vast majority of our population is dependent on the public health care system and a considerable number of patients have to travel long distances to reach a major centre. Referral centres suffer from a lack of trained personnel (nursing staff, technologists, anaesthetists, paediatricians, paediatric cardiothoracic surgeons and cardiologists) as well as a lack of adequate infrastructure and resources.⁽¹¹⁾ The combination of these lead to overburdened referral centres, delayed hospital admissions and long surgical waiting lists. As a result, children with heart disease present late or develop complications such as heart failure and pulmonary hypertension – further increasing morbidity, mortality and the burden of childhood heart disease on available resources.

Improvements in antenatal care, primary healthcare and access to clinics will inevitably lead to increased detection of congenital heart disease which, in turn, will increase the demand for specialised services. Moreover, South Africa has an increasing number of survivors of CHD leading to a growing number of adults with congenital heart disease. These grown up congenital heart disease patients require multi-disciplinary support in addition to a CHD specialist. Currently, there is no dedicated service that can deal with this ever growing population.

Paediatric cardiac services are unique in the sense that they require specialised services and infrastructure to deal with patients. The majority of services can only be delivered by experts in the field and there are few aspects that can be delegated as it requires a dedicated and experienced team of nursing staff, technologists, perfusionists, anaesthetists, congenital cardiothoracic surgeons and paediatric cardiologists. In South Africa, the vast majority of paediatric cardiologists work in the public sector. However, numbers are small due to different reasons, namely restricted training and specialist posts, challenging working conditions, inadequate resources and maintenance of infrastructure as well as limited career opportunities. A combination of all these factors lead to the poor retention of skilled personnel.

In summary, a significant proportion of childhood cardiac disease remains undetected and even those that are detected are disadvantaged by the deficiencies in infrastructure and thus do not receive suitable intervention.

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WHAT IS REQUIRED?

Political willingness and the establishment of public health policies to address deficits and flaws are pivotal in improving the situation and ensuring sustainability. Key interventions should include:

- Improved training and retention of all professionals.
- Increased awareness of childhood heart disease among healthcare workers and the public.
- Early detection of childhood congenital heart disease: antenatal and postnatal screening.
- Providing appropriate infrastructure and equipment to deal with the affected children.
- Expanded clinical research in the field of paediatric heart disease.

Virtually all public sector units have established outreach programmes to improve detection and access to cardiac services. However, these are hampered by the lack of personnel and resources. Interventional cardiac programmes have been developed at all centres and contribute to reducing the load on cardiac surgery. The contribution of percutaneous closure of patent ductus arteriosus, atrial septal defects and ventricular septal defects to reduce the surgical load should not be underestimated. Several academic centres have developed interventional skills that should be treasured and protected. A number of original research works have been published and, in association with the South African Heart Association, national registries are being developed.

It is clear that congenital cardiac services have come a long way in our country. South Africa's tertiary units have the willingness to render appropriate care, but need to be actively supported. Cognisance should be taken that the number of paediatric cardiologists and congenital cardiothoracic surgeons are threatened and these vulnerable subspecialties should be actively supported. With improved primary care, the number of patients will exponentially increase. It is our responsibility to be advocates for our countries' children suffering from paediatric heart diseases. But, are we being heard?

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