

# Uniting to address paediatric heart disease in Africa: Advocacy from Rwanda

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## INTRODUCTION

Across the African continent countries have made significant gains in improving child survival by controlling infectious diseases, upgrading national immunisation programmes and expanding access to maternal, neonatal and basic primary health care. As the international community considers setting new global and national targets for reducing child mortality in the post-2015 development agenda, strengthening entire national health systems – including human resource capacity, infrastructure, access to medicines and information systems – is the paramount priority. Indeed, many

## ABSTRACT

**Paediatric heart disease causes death or disability in 15 million children around the world each year – a figure staggeringly disproportionate to available and relevant international funding and support. Although 80% of the burden of cardiovascular disorders fall in low- and middle-income countries, poor countries have a very limited capacity to build a system of care to address heart disease, including prevention, care, control and research. In this article, authors who work in or with Rwanda's public sector aim to describe the current state of heart disease among children, what is currently being done to manage care and future directions for the national programme. As the world turns its attention to non-communicable diseases and seeks to ensure that they find a prominent place in the post-2015 development agenda, it is essential to ensure that children are not left behind.** SAHeart 2013;10:440-446

countries in Africa are now addressing complex chronic diseases that have not previously been confronted, including cardiovascular diseases which require not only robust and integrated health care delivery platforms but also highly specialised care. In this article authors present the case of Rwanda as an example of a low-income country committed to establishing programmes to tackle the burden of paediatric heart disease.

Fifteen million children around the world die or are disabled each year due to heart disease.<sup>(1)</sup> Rheumatic heart disease, a clinical sequelae of inadequately-treated group A streptococcal throat infection, kills up to 345 110 people every year,<sup>(2)</sup> and remains one of the largest preventable burdens of disease in the world.<sup>(3-5)</sup> Endomyocardial fibrosis (EMF) also takes a massive toll on the poor living along the equator, though research has been sparse since its discovery in 1947 and the cause of EMF remains unknown.<sup>(6-8)</sup> Up to 50% of children born with congenital heart defects in poor countries will succumb within the first month of life.<sup>(9)</sup>

Low- and middle-income countries bear 80% of the burden of heart disease,<sup>(10)</sup> despite the fact that most types of heart disease are preventable or highly treatable with the appropriate tools and training. Even children born with congenital heart disease, when detected and treated early, can often make a full recovery. And yet, despite major advances in scientific knowledge and clinical techniques that have increased preventive, diagnostic and treatment

options in wealthy countries in recent decades, a lack of access to up-to-date information, specialised clinicians and adequate resources in settings with the largest burdens of disease widens and entrenches disparities in risk and outcome. Indeed, about 4 000 cardiac units existed in 2002, but served a mere 7% of the world's population.<sup>(11)</sup>

### THE RWANDAN CONTEXT

Rwanda is a small, landlocked, low-income country in East Africa, with a population of 10.5 million<sup>(12)</sup> and a gross national income per capita of \$570.<sup>(13)</sup> Mortality attributable to HIV, tuberculosis, malaria and other causes of preventable child and maternal death declined precipitously over the past decade.<sup>(14)</sup> Deaths among children under the age of 5, for instance, have declined by 70.4% from 2000 to 2011, falling from 183 per 1 000 live births in 2000 to 54.1 in 2011.<sup>(15)</sup> While Rwanda's life expectancy was the lowest in the world throughout most of the 1990s, Rwandans born today can expect to live until at least 56 years.

Health insurance coverage is near universal: the vast majority of Rwandans are enrolled in public (92%) or private health insurance (6%). The 1994 genocide that decimated the population also impacted upon the number of health care workers. But despite persistent gaps, the health workforce has now grown to a cadre of 625 physicians, 8 513 nurses and 240 midwives who provide care in the country's mostly new or rebuilt 42 decentralised hospitals and 473 health centres. Nearly 45 000 community health workers are elected as volunteers and trained in health promotion as well, thus providing basic diagnosis and treatment in Rwanda's 15 000 villages. Strong partnerships have been formed with non-governmental and international organisations in recent years.

In 2009, the Government of Rwanda incorporated non-communicable diseases (NCDs) into its Economic Development and Poverty Reduction Strategy as a "cross-cutting development issue," mandating that each sector of government devise a strategic plan for contributing to the national response to the mounting burden of heart disease, cancer, diabetes, chronic respiratory conditions and major mental illness. The Ministry of Health has worked with partners to prepare its health system for a changing demographic and epidemiologic profile, including a growing prevalence of cardiovascular conditions across age groups.

During the first decade of the national response to HIV/AIDS, Rwanda's health authorities discovered that unless new programmes are designed with the unique vulnerabilities and needs of children in mind, challenges of linkage to care and retention quickly lead to children being left behind.<sup>(16)</sup> The Ministry of Health has therefore endeavored to ensure that new efforts to expand cardiac care

capacity in Rwanda prioritise the needs of paediatric patients. Although research is scant and programmes limited, this article aims to capture the current state of Rwanda's response to paediatric cardiac diseases and disorders, with a focus on congenital heart disorders and rheumatic heart disease, and to offer recommendations for the near future.

### CONGENITAL HEART DISEASE

Most congenital cardiac diseases arise as early presentations. Common symptoms may include cyanosis, dyspnea, hepatomegaly, diaphoresis, feeding intolerance and failure to thrive. A minority of cases remains undetectable or asymptomatic through infancy and later manifest during adolescence or young adulthood. The key to survival in most cases however is early detection and intervention within the first year of life, particularly in cases of heart defects with significant left to right shunt. Diagnosis and treatment for congenital cardiac disease has undergone impressive evolution over the past few decades, with a noticeable shift from efforts to decrease post-operative mortality to those emphasising improved quality of life and decreased morbidity. For example, the advent of sophisticated screening and detection options has now made the diagnosis of many defects possible "in utero", allowing children born with congenital heart disease to undergo timely intervention and lead normal lives.

Availability of modern scientific and technological advances, however, is largely limited to children born in high-income countries (and even then access is stratified according to family income level, insurance coverage and access or proximity to the right tertiary facility, among other factors). Late presentation or poor detection of congenital heart defects, as well as co-morbid conditions, deepens these inequities. Even the most basic diagnostic tools – pulse oximetry use in neonatal care and x-ray, echocardiography and electrocardiography (ECG) – are not available in public facilities in many low- and middle-income countries. In-service training for cardiovascular care is also sparse. Such inequitable distribution of science, training, equipment and financial resources results in hundreds of thousands of unnecessary deaths among children born with congenital heart disease each year in the poorest countries.

In Rwanda, the Ministry of Health's 2012 Clinical Treatment Guidelines for Paediatrics include a thorough section on case detection for congenital heart disease. These guidelines are for outpatient diagnosis (passive case-finding) and inpatient care, as standard cardiovascular investigations are not yet conducted as part of routine neonatal or paediatric care. While most hospitals have x-ray capacity, echocardiography and ECG are only consistently available at 3 tertiary care facilities, all located in 2 main cities, Kigali and Butare. Treatment options are few in Rwanda: the population

of children with congenital heart disease diminishes as the cohort ages secondary to mortality associated with their underlying condition. A small number (<40) of paediatric heart surgeries are performed each year by visiting foreign teams. One important step towards preventing congenital heart disease is the nationwide rollout of the rubella vaccine in March 2013, which will undoubtedly eventually reduce the burden of paediatric cardiac disease related to maternal rubella infection.

While plans to develop a national registry for congenital and acquired heart disease are in progress, the only data currently available for review is derived from intake records of one of Rwanda's 2 paediatric cardiologists, who serve in Kigali University Teaching Hospital (KUTH), a public referral facility. Between 2010 and 2013, a total of 321 patients were diagnosed with congenital heart disease at KUTH. Among these patients, 218 were aged 5 years or younger, illuminating – if anecdotally – the need for early cardiac intervention. Forty-eight patients presented with Trisomy 21, or Down's Syndrome, in addition to one or multiple congenital heart disorders, such as atrio-ventricular septal defect (often presenting as endocardial cushion defect), patent ductus arteriosus and tetralogy of fallot. About half of the cases were referred from locations within Kigali City Province, or from districts immediately adjacent to Kigali City Province in one of Rwanda's other 4 provinces. Given that population distribution in Rwanda is fairly even across provinces, these data provide clear messages about the need for clinical outreach to rural areas.

After symptom onset and diagnosis, case management is often commenced at KUTH before patients are referred to district hospitals closer to home for follow-up. Most families pay for 10% of inpatient and outpatient care (for any disease, not just heart disease) under the community-based health insurance scheme; the poorest 25% of the population do not pay for care for any health issue. Essential medicines for congenital heart disease are available to patients with maximum 10% co-pay and include lasix, captopril, iron supplement, propranolol, aldactone, digoxin, sodium bicarbonate and morphine. Some of these drugs are given within the hospital setting, others are prescribed and taken at home. Oxygen delivered by mask is not consistently available for all children in need at all district-level facilities, though the Ministry of Health considers this a priority area for improvement. As with all chronic diseases, it is just as "essential" that the patient be provided with adequate nutritional support in order for treatment to be deemed successful, though many public facilities in Rwanda do not provide food to patients. Finally, especially given the limited options for surgical intervention for children born with heart disease in Rwanda, access to medicines for palliative care is critical. Drugs for pain alleviation, including morphine, paracetamol, codeine and pethidine,

are available at all district and referral hospitals and efforts to expand supply chains and training to health centres and communities are underway. Multiple drugs – either for the management of dyspnea or other associated heart failure complications – are available at district and referral hospitals.

The majority of congenital heart disorders can be treated with significant relief of symptoms with cardiac surgery, if not cured. Survival is often predicated upon carefully planned, staged procedures with lifelong monitoring and follow-up care. For all cardiac surgical procedures among children with congenital heart disorders, a specialised level of expertise is required beyond that of routine cardiac surgery capabilities. Apart from a few centres performing neonatal cardiac surgery in northern and southern Africa, cardiac surgery is not available to the rest of the continent. Most affected babies will die in the first month or year of life or become inoperable for different reasons. For Rwanda and other countries without a domestic cardiac surgery programme, there arises the harsh reality of rationing the opportunity to receive life-saving cardiac surgery when available by visiting teams or by international referral. This selection is taxing on all involved, as the number of critical cases that require immediate surgical intervention always exceeds available resources.

### ACQUIRED CARDIAC DISEASE

Although many diseases are considered acquired heart disorders among children, the authors present the case of rheumatic heart disease (RHD) in Rwanda given the availability of data and the high burden of disease. Beginning as a seemingly innocuous sore throat, the prequel of RHD is a common infection with the streptococcal antigen (group A streptococcal bacteria), usually among children and young adults. As many as 3% of children who develop streptococcal infection in the throat and go untreated (with penicillin), will develop acute rheumatic fever affecting the body's connective tissues – especially those of the heart, joints, brain or skin.<sup>(17)</sup> Around half of patients with acute rheumatic fever present with cardiac inflammation, mainly involving the valvular endocardium. Although the initial attack can lead to severe valvular disease, RHD most often results from cumulative valve damage due to recurrent, symptomatic or minimally-symptomatic episodes of acute rheumatic fever, which is often not associated with symptomatic pharyngitis and suggests that it might be insidious at onset.

One key challenge in addressing RHD lies in the lack of reliable data capturing the true burden of disease – i.e. precise geographical, age and gender distribution and health systems measurements such as where and when care is being sought, by whom and at what cost. Health authorities in many countries rely on regional estimates of the burden of RHD given the absence of national disease registries

and underreporting or misdiagnosing of acute and chronic cases of RHD.<sup>(18)</sup> While some countries have executed robust screening and treatment programmes specific to RHD,<sup>(19-21)</sup> few structured national programmes for RHD prevention and care have been documented in resource-poor countries given limited funding, research capacity and adequate skill level and mix of health workers. Lack of adequate training or fear that a patient may have a fatal allergy to penicillin on the part of the health professionals may also influence care delivery.

Approximately 1 188 000 disability-adjusted life years (DALYs) are lost to RHD in sub-Saharan Africa, with a rate of roughly 138.3 per 100 000 population.<sup>(22)</sup> The Global Burden of Disease 2010 study provides crude modeled estimates of the burden of RHD and other cardiac conditions in Rwanda, though none of the weak underlying data on which these are based were actually collected in East Africa. Despite the paucity of data, anecdotally, Rwanda's 2 paediatric cardiologists are noting an increase in clinical presentations of critical or late-stage RHD among their paediatric population. It may be the case that this upsurge is in part due to the improvements in Rwanda's health system and health insurance coverage over recent years, in which patients can more easily than ever before be referred up to higher levels of care. Further research is required to better understand this relationship.

The highest level of consistently available in-country care, however, is still medical intervention. In the same 2010 - 2013 database created by the paediatric cardiologists, 96 patients were diagnosed with acquired heart disease (AHD) and 66 of those patients had rheumatic heart disease. The majority of patients with AHD were girls (60 versus 36), and the average patient age was 12 years. Two cases were diagnosed as endomyocardial fibrosis (EMF) and 27 others with other heart diseases (e.g. dilated cardiomyopathies and pericardial diseases among others). Among those children with RHD, more than half of all cases occurred in 12 - 16 year-old children.

Recognition of pre- and early rheumatic heart disease remains a major impediment to care delivery, as family members, teachers, or even clinicians may not know or consistently associate symptoms of streptococcal throat infection with a potentially fatal disease, especially when a child recovers without any or any significant treatment. Further, given that there are not yet consistent school health programmes nor annual check-ups for healthy children in Rwanda, it is more likely that the child would come for a visit if symptoms persisted for longer than would be considered a normal duration. Broad-reaching sensitisation programmes regarding strep throat infection and linkages to cardiac disease so far do not exist in Rwanda.

A second missed opportunity in diagnosis occurs when symptoms of rheumatic fever and RHD (e.g. fatigue, malaise, repeated chest

infections and fevers) are not immediately associated with compromised cardiac function. Those patients that do present with symptoms and are diagnosed with RHD are often beyond medical management and often require urgent, if not emergency, surgical therapy. Out-of-pocket payments for emergency medical attention, lengthy hospital stays, and lifelong warfarin therapy are additional barriers to care – even with national health insurance covering 90% or more of the costs. Furthermore, some parents of patients with RHD report having first sought care from traditional healers – though this care-seeking behaviour requires further research. Although traditional medicine in Rwanda is regulated and monitored by the Ministry of Health, any delays in seeking medical care further diminishes the patient's chance of survival.

For most children who develop RHD – as for those born with congenital heart disease – surgery represents the only option for survival. Over the past several years, the health sector in Rwanda has relied upon a combination of strategies to address the need for cardiac surgery while the country strengthens its own human resources and infrastructure capacity for these types of interventions. Rwanda has been able to augment the surgical care provided for paediatric cardiac disease through a unique partnership between the Rwanda Ministry of Health and 4 expatriate teams that now rotate in-country on a consistent basis, providing cardiac surgery for paediatric and adolescent cases (Panel 1). Each team, representing a breadth of surgical expertise, has made important contributions to early steps in the establishment of training programmes for cardiac surgery, perfusion and cardiac nursing, among other specialisations. The unified goal of the teams is to provide care during visits and assist Rwanda towards establishing a self-sustaining, domestic, comprehensive cardiac programme and regional referral and training centre to address the surgical burden of paediatric cardiac disease. Recent media attention on RHD in Rwanda has also ushered in new international interest, rendering the country's response to RHD even timelier.<sup>(23)</sup>

## FUTURE DIRECTIONS

In order to mobilise resources and design effective interventions to address congenital and acquired heart disease in children, policy-makers in Rwanda and across Africa need more and better data. Despite the fact that RHD is responsible for nearly 3 times the number of deaths caused by measles,<sup>(24)</sup> it is almost completely absent from the global health agenda, receiving just 0.07% of all global health research funding in 2009.<sup>(25)</sup> And while total deaths from RHD have declined around the world in recent decades, levels have remained constant in Africa,<sup>(26)</sup> meaning that disparities continue to grow as detection, care and treatment improve elsewhere. Research is also needed to document the burden of

congenital heart disease and all forms of acquired paediatric heart conditions beyond rheumatic disease. Assessing the effect on child health outcomes in Rwanda following the rubella vaccine rollout in March 2013 will also be important, as this type of public health intervention has the potential to improve the health of Rwanda's citizens in the future. In order to accurately register and manage the burden of disease, more physician specialists in paediatric cardiology are necessary. Furthermore, the tools and equipment for early detection and proper diagnosis, treatment and follow-up of cases are critical to advancing this national programme. Digital infrastructure for recording and follow-up of heart disease patients – similar to Rwanda's national HIV/AIDS informatics system, TRACnet<sup>(27)</sup> – would lessen the time between research and action and improve longterm prognoses, particularly for RHD patients.

Beyond studies on prevalence and incidence, another research priority – under the categorisation of implementation science – relates to the care pathway for paediatric heart disease in Rwanda. In order to establish new programmes, the health sector would need to document the following: (1) the currently accessible care pathway for publicly insured patients in both rural and urban areas and the pathways taken by those who are uninsured, (2) the pathway patients and their parents are taking in reality (including the involvement of traditional healers) and (3) where patients are falling off the continuum of care. This type of health care delivery research would enable the Ministry of Health and its affiliated institutions to establish a care delivery value chain that responds to the population.

From a programme intervention standpoint for rheumatic heart disease, primary and secondary prevention are priority areas for Rwanda. The prevention of streptococcal throat infection by improving living standards and decreasing overcrowding at the household level is in line with Rwanda's Economic Development and Poverty Reduction Strategy. For secondary prevention, the health sector should focus on removing barriers to accessing penicillin prophylaxis. Research would inform which barriers to prioritise, however, this would most likely include sensitisation campaigns directed at the population (i.e. families, teachers, local authorities, community health workers, traditional healers) on the dangers of inaction. This would likely include reducing the time from symptom onset to treatment by examining barriers to accessing medicines.

Case finding is interrelated to all the aforementioned factors and would include improvements in timely recognition and referral of congenital and acquired heart disease (including early signs and symptoms of rheumatic fever) by nurses and physicians. Clinical knowledge advancements would call for continuing professional

development courses offered to both physicians and nurses, and could be coupled with Rwanda's new partnership with 23 American academic institutions to significantly enhance human resources for health in Rwanda.<sup>(28)</sup> Various innovations in technology for medical education and consultations between clinicians should also be pursued where most needed. The health sector may also consider echocardiography- or pulse oximetry-based screening in schools, hospitals or clinics in the early stages of developing its paediatric heart disease programme. One of the expatriate surgical teams, Team Heart, from Boston, USA, in partnership with the Rwanda Heart Foundation, carried out the first echo-based RHD screening of 2 693 school-aged children (6 - 16 years) in 10 randomly selected schools in the Gasabo District near Kigali in September 2011. Such studies can pave the way toward strengthening the national response.

## CONCLUSION

Rwanda's health sector already has a history of commitment to ensuring chronic care at the community-level.<sup>(29)</sup> Buttressing that system to incorporate care for paediatric heart disease would provide more ways for children who have undergone cardiac interventions to live long and healthy lives. At the moment, cardiac surgery is being performed both in Rwanda, led by foreign teams, and outside of the country. The teams that perform surgery in-country have sought to strengthen capacity among Rwandan colleagues, though systematic advances are long overdue. A fully functioning cardiac surgical centre in Rwanda, run by highly trained cardiac surgery teams is a major goal of the programme. One Rwandan physician is currently a cardiac surgery resident outside of the country and there is reason to be optimistic that the creation of such a centre is in the near future. The full components of a cardiac surgery team (surgeons, cardiologists, anaesthetists, nurses, perfusionists and so forth) will also be critical to establishing a cardiac surgery centre in Rwanda. Authors of a recent article stated that one centre for every one million people would be required to handle the burden of cardiac diseases around the world, most of which are currently neglected in global funding priorities.<sup>(30)</sup> Post-operative care would be a vital component of a cardiac surgery centre, as well as close monitoring of procurement and supply chains, as is routine already.

As the world turns its attention to non-communicable diseases and seeks to ensure they find a prominent place in the post-2015 development agenda,<sup>(31)</sup> it will be essential to ensure that children are not left behind. Paediatric cardiac diseases constitute a growing burden of preventable and highly treatable morbidity and mortality in many regions including Africa, and an agenda focused primarily on behavioural risk factors like smoking and diet will not meet the needs of affected children and families. Data on children's access to antiretroviral therapy (28%) compared to adults' (53%) around the

world<sup>(32)</sup> provide a sobering reminder of the consequences when systems are not explicitly designed with children's vulnerabilities in mind. The global health community now faces an opportunity and a responsibility to guarantee that equitable and effective approaches to addressing paediatric cardiac diseases are a key part of efforts to fulfill the unfinished promise of the fourth Millennium Development Goal.

## **PANEL 1: PAEDIATRIC CARDIAC INTERVENTIONS IN RWANDA: THE EXPERIENCE OF PARTNERS**

### **Chain of Hope (Belgium)**

Chain of Hope (COH) is a non-governmental, humanitarian organisation based in Brussels, Belgium which was founded in 1997. The goals of COH are to provide surgical services for children, transfer skills to local teams and assist in infrastructure planning. After a first visit by a Rwandan physician in 2004, COH has since hosted 2 cardiologists, one anaesthetist and one intensive care physician for 2-year fellowships in Belgium. Since 2007, over the course of 14 visits, COH partnered with the Ministry of Health of Rwanda to diagnose 320 children, perform cardiac catheterisation on 79 children (a technique used for the first time in Rwanda)<sup>(33)</sup> and provide surgical treatment to 23 children. The COH team generally includes 2 people for evaluation and diagnosis, and 6 - 10 people for interventions, staying about one week in Rwanda and working with local personnel. Regular visits each year by all partner teams have initiated a dynamic process of cardiac care in Rwanda and stimulated the upgrade of equipment available. Partnerships have enabled foreign teams to work toward a shared end goal with the Ministry of Health: for Rwanda to have a self-sustaining programme addressing paediatric cardiac disease.

### **Healing Hearts Northwest (USA)**

The first surgical experience of Healing Hearts Northwest took place in 2010 and surgical visits in 2011 and 2012 have followed. The team has served 50 patients during this time, including approximately 8 congenital cases, one pericardiectomy and the remainder chiefly patients suffering from rheumatic heart disease. There have been significant gains in the knowledge and capabilities of the Rwandan counterparts, with an increasing percentage of care provided by Rwandan nurses. Likewise substantial knowledge and skills have been demonstrated by a Rwandan cardiac anesthesiologist and pump technician. Even with excellent progress having been made towards building an independent, domestic programme, challenges continue including retaining the individuals who develop these skills locally and establishing a reliable infrastructure support with regards to local purchasing of supplies and equipment maintenance. Recognition of these challenges and embracing solutions will

allow a fully functioning cardiac surgical centre in Rwanda to become not only a goal, but a fully fledged reality.

### **Operation Open Heart (Australia)**

Operation Open Heart (OOH) commenced work in Rwanda in April 2006 at the invitation of the Rwandan Ministry of Health to assist in meeting the surgical needs of those suffering with congenital and rheumatic heart disease. From OOH's inception in 1986, its goal has been to provide cardiac surgical services to countries where this service is not readily available while at the same time providing skills transfer and training to the local team, assisting also in infrastructure planning. The end goal being the creation of such a self-sustaining programme in Rwanda. The team of 35 - 40 personnel visits Rwanda for a period of 17 days at a time, including periods for setup, patient screening, surgeries and post-operative care. While other visiting surgical teams to Rwanda are proficient in adult surgery, OOH has focused on paediatric needs and to-date, after 6 visits to Rwanda, 136 children and adolescents have received surgical care.

### **Team Heart (Boston)**

Team Heart (TH) is a non-governmental, humanitarian organisation based in Boston, Massachusetts. The TH Mission is the development of a comprehensive programme to eradicate RHD. This includes annual trips to perform cardiac surgery on patients with advanced RHD (2008 - 2013; 86 patients operated), a screening programme (2011; ~2 800 school-aged children screened with echocardiography), education of Rwandan healthcare personnel (Rwandan surgeon training in South Africa; 2 trained perfusionists, one anesthesiologist, 10 - 20 nurses in and out of operating theatre trained and on site) and working with the Ministry of Health and Medical School of the National University of Rwanda to improve postoperative care for out patients. The ultimate goal is the establishment of a Rwandan-staffed hospital capable of providing comprehensive cardiac care for the people of Rwanda and surrounding countries.

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