CHILDREN'S HEART DISEASE

Children's heart disease in sub-Saharan Africa: Challenging the burden of disease

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INTRODUCTION

"Where you live should not determine whether you live." - Bono

The vast majority of African children with heart disease have no access to treatment.

Once the "cradle of humankind" and home to major civilisations, Africa is a place of poverty with a burden of disease unlike anywhere else. The world's 20 least developed nations are in sub-Saharan Africa.⁽¹⁾ Although the role of developed nations in destabilising Africa bears much discussion, there are many other factors, including poor governance, corruption, a lack of democracy and civil unrest, while political priorities seldom include healthcare.⁽²⁾ International aid continues to pour in to the continent, but is offset by crippling foreign debt, which costs countries more than the aid received, and four to six times more than is spent on healthcare.^(2,3)

It is in this complicated context that many of us would seek foster care for children with heart disease, a largely hidden noncommunicable disease that is understandably both understudied and for the most part ignored.⁽⁴⁾

ABSTRACT

Children with heart disease in Africa have little or no access to treatment of any kind, and cardiac surgical services are virtually absent outside a handful of centres in a few of the wealthier nations. There is little reliable data concerning the prevalence of congenital or acquired heart disease in African children, but there is sufficient information to indicate that the burden of cardiac disease is vast. This major non-communicable disease is largely hidden, overshadowed by the incidence of communicable diseases. There is as yet little evidence of the hoped-for epidemiological transition toward non-communicable diseases amongst children in Africa. The burden of congenital heart disease is only part of the problem, with rheumatic heart disease (RHD) remaining the commonest cardiac problem, related to poor socioeconomic conditions. RHD is the most preventable form of cardiac disease, yet there is little preventive work being done. The many obstacles to developing paediatric cardiac care are discussed, and some possible ways forward are proposed. SAHeart 2010; 7:18-29

Africa's population was estimated at 922 million in 2005, having doubled in 25 years, and quadrupled in 50 years;⁽⁵⁾ it was expected to exceed one billion by the end of 2009. Children's health issues are particularly prominent because of the large "youth bulge" in population distribution; more than half of Africa's people are under 25 years of age.⁽⁵⁾ (Figure 1.)

The estimated under-5 mortality for sub-Saharan Africa is 148 per 1 000 live births: that is 6 million children per year, 16 000 per day, one child every five seconds...⁽⁶⁾ mostly due to communicable diseases. The needs of children with non-communicable diseases like heart disease are swamped; yet without appropriate treatment about one in three children born with congenital heart disease will die within the first month of life.⁽⁷⁾ In the case of rheumatic heart disease one in five will die by the age of 15 years, and almost 4 in 5 will be dead by the age of 25.⁽⁸⁾ "Cardiac Surgery is the first request from a lot of poor countries." - Daniel Sidi, Nov.3rd 2008, SAHA meeting.

BURDEN OF DISEASE

The "big three" communicable diseases – malaria, HIV and tuberculosis – dominate, and the "epidemiological transition" toward non-communicable disease that is reportedly beginning in the adult population⁽⁹⁾ is not yet seen for children. Reasons for this relate to persistent poverty and malnutrition, lack of basic sanitation and clean water, and poor access to healthcare.⁽¹⁰⁾ Cardiac diseases simply add to this enormous health burden for the average child.

Acquired heart disease

Acquired heart disease in Africa is predominantly rheumatic heart

disease (RHD), consequent upon recurrent attacks of acute rheumatic fever (ARF). A single attack of ARF may progress to RHD, but most RHD results from the cumulative damage of repeated attacks.^(11,12,13,14)

Over the past century the incidence of ARF and RHD has declined steeply in developed countries; the initial and most rapid decline was before the antibiotic era, due mainly to improving socioeconomic conditions.^(15,16,17) RHD is today rarely seen in developed nations;^(18,19,20) already by the 1980s it was thought to be virtually eradicated.⁽²⁰⁾ Yet RHD remains the most common form of cardiac disease in children and young adults in Africa and a major public health concern.⁽¹⁶⁾ It is the most preventable form of cardiac disease, though difficult to treat effectively without surgery,⁽¹³⁾ which is expensive, generally unavailable, and involves high-cost prostheses;⁽²⁰⁾ it is also only a partial solution, especially in a



FIGURE I: Age pyramid: South Africa

The South African age pyramid illustrates the classic prominent "youth bulge" of developing nations. The bulk of the population is under 25 years old, the age group most affected by the twin epidemics of acquired (rheumatic) and congenital heart disease.

Source: United Nations World Population Prospects: 2008 Revision

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resource-poor setting where adequate coagulation control is $\mathsf{unlikely}^{(21,22,23)}$

While there is no reliable data on the incidence of ARF in Africa, ⁽²⁴⁾ the reported incidence of RHD varies widely. In developed countries it is less than 0.5 per 1 000 population,⁽²⁵⁾ but is high in poor nations, for example 78 per 1 000 in Samoa.⁽²⁶⁾ In Africa, early reports based on auscultatory screening of school-going children gave incidences from 2.7 to 20 per 1 000 population.^(16,27,28,29) Recently Marijon et al reported an incidence in Mozambique of 30.4 per 1 000 using echo-based screening of schoolchildren,⁽³⁰⁾ probably a better estimate. Because of the difficulty in obtaining data, it is possible that the true incidence in many areas is even higher. Using echocardiography, Bonhoeffer reported an incidence of mitral regurgitation in rural Kenya of 62 per 1 000.⁽³¹⁾

One third to half of all cardiac hospital admissions in developing countries are due to RHD, with an average length of stay of 3 to 4 weeks.^(32,33) The typical age affected is 5 to 18 years.^(32,33,34) There is widespread evidence that in developing nations RHD occurs at a younger age than in developed countries, and also progresses more rapidly, though this may reflect more frequent attacks of ARF,^(33,35,36,37,38,39,40,41) as without intervention, the sequence of events is predictable: after the initial infection with Lancefield

group A β -haemolytic streptococci 3% of patients develop ARF approximately 19 days later.⁽⁴²⁾ At reinfection, the incidence increases sharply to more than 75% of patients.^(43,44,45)

During ARF, carditis is present in 40-80% of patients; of those with carditis, 90% will develop chronic progressive RHD.^(46,47,48,49) (Figure 2.)

The initial carditis is characterised by fibrinoid collagen degeneration followed by a proliferative phase 1-6 months later. At that stage, the pathology is defined by annular dilatation, chordal elongation and anterior leaflet prolapse.⁽⁵⁰⁾

Thus the hallmark of acute rheumatic carditis is the pan-systolic murmur of mitral regurgitation (MR). If heart failure occurs in the wake of acute carditis with MR leading to LV dilatation, only surgical correction can lead to improvement.⁽⁵⁰⁾ The severity of LV dysfunction correlates more with the extent of the valvulitis than with the myocardial injury, although myocarditis co-exists in 30% to 70% of cases.⁽⁵¹⁾ Eighty to 90% of those with severe MR during an ARF attack will develop clinically significant RHD. Of 9-year old children surviving ARF, 20% will be dead by the age of 15 years.⁽⁵²⁾ and more than 70% by 25 years.^(53,8) The majority of the latter group will have mitral and aortic regurgitation at death. Due to



FIGURE 2: An outline of the process from streptococcal infection to rheumatic heart disease. Millions are quietly dying from RHD in Africa, with virtually no access to treatment and very little done to prevent acute rheumatic fever.

the chronic valvulitis, survivors typically develop mitral stenosis on top of MR,^(53,54) its incidence increasing with age.⁽³⁷⁾

The economic effects of RHD on communities are well described.^(53,55,56) Without access to surgery, the costs of repeated hospitalisation are significant. There are also intangible costs from premature disability and death, endocarditis and stroke, and loss of schooling and training.^(25,35,55,57,58,59,60,61) Two-thirds of children with RHD leave school early.⁽⁶²⁾ RHD indirectly affects national productivity, the young adults it affects being the most productive segment of the population.^(60,62,63) RHD is also responsible for 10% of maternal deaths,^(64,65) and is the main predisposing factor for infective endocarditis in Africa,(66,67,68,69) occurring at a mean age of 27 years.(70)

Congenital heart disease

Incidences of "significant" congenital heart disease (CHD) (i.e. what will require expert cardiological care at some stage) are generally reported at about 1% of live births or slightly less,^(4,71,72,73) with eight common types of lesions making up 85% of all clinically significant CHD (ventricular septal defect, atrial septal defect, patent ductus arteriosus, pulmonic stenosis, tetralogy of Fallot, coarctation of the aorta, aortic stenosis, atrioventricular septal defect.)⁽⁷²⁾

Most reliable studies indicate that, with only minor variations, the incidence is constant worldwide, across geographic and ethnic backgrounds, and in spite of variations in socio-economic conditions.^(4,72,74) Thus it is valid to extrapolate these estimates to developing nations.

There are factors that may in fact suggest a higher estimate. For example, CHD may be undetected in infancy, not being included in studies that tend to focus on infancy;(74) one in four cases of CHD in the UK is diagnosed later in childhood.⁽⁷⁵⁾ In the USA at least 10% of patients with CHD first present in adulthood.⁽⁷⁶⁾

Without appropriate treatment, about half of those born with significant CHD will die in infancy or early childhood, a third of them within the first month of life.⁽⁷⁷⁾ Most who survive longer will become debilitated by the cardiac defect.^(7,77) Thus, of the approximately 50 million live babies born every year in Africa,^(5,6)

as many as 500 000 will have significant CHD that will require expert cardiological care; about half will die within a few years of birth. There is also a large pool of older children and adults with CHD that survived the early years who are debilitated by the disease. This is while paediatric cardiac medicine has advanced to the point that outcomes for children with heart lesions is in most cases excellent.

The exact cause of CHD is not known in most cases, though there are known contributory factors. These include genetic defects and chromosomal abnormalities, maternal intrauterine viral infections such as rubella, certain medications taken in early pregnancy, consanguineous marriages, etc.⁽⁷⁸⁾

PREVENTION

Nowhere is the absurdity of a lack of prevention of RHD, in the face of heroic efforts to treat it, better described than in McLaren's 1994 statement likening it to "attempting to mop up the water on the floor while leaving the faucet open."(79) On purely economic grounds, it is clear that prevention of RHD is an urgent need.^(8,33)

ARF can be prevented through timely antibiotic treatment for streptococcal sore throat (primary prophylaxis); progression to RHD through recurrent attacks can be prevented by ongoing antibiotic therapy (secondary prophylaxis).⁽⁸⁰⁾ Secondary prophylaxis appears to be a most cost-effective strategy for Africa.(33,80) It may be unrealistic to expect to see advanced paediatric cardiac care in the near future in poor countries, but it is possible that prevention of ARF/RHD could be incorporated into most basic health systems, as the Indian example shows.⁽⁸¹⁾

A welcome development in this regard was the adoption, at the first All Africa Workshop on Rheumatic Fever and Rheumatic Heart Disease in 2005, of the "Awareness, Surveillance, Advocacy, Prevention" (A.S.A.P.) proposal, aimed at mounting an effective prevention strategy in Africa under the auspices of the Pan African Society of Cardiology (PASCAR).⁽⁸²⁾

TREATMENT

History

Paediatric cardiac surgery in Africa was inaugurated in March 1958 when Christiaan Barnard closed an ASD in an 8 year-old child at the Red Cross War Memorial Children's Hospital in Cape Town. Over the ensuing decade children's heart surgery centres sprang up in most of the major centres in South Africa, and also a few in Africa, including in Egypt and Uganda. However, while this phase of rapid growth proceeded briskly in the developed world, it faltered in Africa for many reasons. Some first-class medical facilities were lost through skilled personnel leaving for greener pastures, some like the Makerere University unit in Uganda were closed in the midst of political strife, and many simply could not afford the ongoing expense. After the Declaration of Alma-Ata was adopted at the International Conference on Primary Health Care in Kazhakstan in 1978,⁽⁸³⁾ government policies shifted further away from tertiary health care funding.

In the early 1970s the well-known period of fly-in missions began, with expert visiting teams operating on a small number of carefully selected patients. At about the same time many non-governmental organisations (NGOs) began funding the transfer of selected indigent patients to first-world units with spare capacity. These attempts to help have been criticised in many ways, primarily for being the proverbial "drop in the ocean" at great expense, though undoubtedly many lives have been saved. It is clear though that unless local healthcare expertise is built up through the process, these exercises are at best not cost-effective, and at worst a waste of donor money that could have been used for something more sustainable.^(23,84,85)

NGOs have generally now shifted focus towards building longterm partnerships with recipient sites with a vision to eventually develop autonomous local services. There is a growing consensus about the need to work together to build regional centres which themselves can become a resource to surrounding areas and countries through satellite outreaches.^(84,85,86,87) Such regional "surgical hubs" could form training and resource bases for surrounding countries, with international aid coordinated at one centre rather than being diluted through multiple small efforts.

NGO-sponsored partnerships (e.g. "Save a child's heart") are pioneering another approach: a cardiologist, or a physician with a cardiology interest and an echo machine, establishes a clinic with diagnostic and post operative follow-up abilities, and basic laboratory facilities. Over a training period of three to 15 months a local team is established, with assistance to procure equipment, and basic surgery gradually begins, complex cases being flown to mentor institutions.

Surgery

One of the dilemmas of RHD in Africa is that it may manifest in children or in adulthood, when those who survive multiple attacks of ARF develop progression of their valve lesions. At this point typically only surgery will help, highlighting the need for both adult and paediatric cardiac surgical services. Paediatric services typically develop on the back of workable adult services, but there are far too few adult services in Africa. Similarly, facilities to monitor anti-coagulation after valve replacement are virtually non-existent.⁽⁸⁸⁾

In spite of years of effort, there is still little cardiac surgery happening in Africa. For example, Nigeria hosted their first fly-in mission 35 years ago, in 1974. Over the subsequent three decades only 102 patients underwent cardiac surgery, about half of them children, some by visiting teams and some by local surgeons.⁽⁸⁹⁾ There are believed to be about 15 trained cardiac surgeons in the country, and yet no active service is available due to lack of infrastructure. Kenya, on the other hand, having begun about the same time, has managed to build a cardiac service spread across four hospitals, including both state-funded and private facilities, and including a basic paediatric service.⁽⁹⁰⁾

Most of Africa relies on flying paying patients, or donor-funded patients, to centres off the continent, or hosting short-term visits of skilled personnel. There is a marked lack of coordination in the latter and some NGOs have not learnt the lessons of sustainability. For example, there has been a surgical team visiting Zambia from Uzbekistan once per year for 14 years, in which time 76 adult patients have had cardiac surgery, but there has been no local infrastructure development.⁽⁹¹⁾

A warning may well be sounded about the South African situation, where the number of children operated on in the state services has decreased significantly over the past decade, and the services are seriously under-serving the population.⁽⁹²⁾

Currently about 2 500 to 3 000 African children get operated on annually for all forms of heart disease, most of them in South Africa

and a small number of other centres.⁽⁹³⁾ A large proportion of these are patients with money or medical insurance to support private care. A further small number has surgery at great expense to donor organisations through fly-in expert teams, or being taken to centres in developed nations. There is a growing willingness in Africa and internationally to work together to improve this situation, but no clear strategy is in place.

New catheter-based technologies, the area of fastest growth in cardiac care these past 10 years, do have potential for Africa. Dr. Philip Bonhoeffer introduced balloon valvuloplasty in Kenya in the early nineties, and has taught local cardiologists how to do the procedures.⁽⁹⁴⁾ Such interventions can reduce costs and improve access to cardiac therapies, though typically costs remain prohibitive.

A further cost-effective alternative to surgery for RHD could be durable valves which need no anticoagulation, implanted through a relatively straightforward catheter-based approach in secondarylevel hospitals. The seeds of this possibility do exist, although exorbitant costs are still an issue. Unhappily most research funding is directed toward first-world needs for both pharmaceuticals and technology.⁽⁹⁵⁾

Other approaches that were commonplace in the early days of cardiac surgery could be appropriate for developing nations unable to afford high tech developments. For example, closed mitral valvotomy using a Logan-Tubbs dilator, which cheaply and effectively saved thousands of lives from 1954 into the 1980s before expensive catheter-based alternatives came into vogue.^(96,97,98) Many cardiac centres still have the old dilators, though the skills required for the procedure are almost lost.

OBSTACLES

If the communicable disease burden amongst children in sub-Saharan Africa should diminish, cardiac diseases will be highlighted as the major non-communicable problem.⁽¹⁰⁾ However, more important than individual diseases are the "prior questions," the issues that drive the problem. If these questions were resolved, the burden of disease would shift toward non-communicable disease, the so-called "epidemiological transition" that is hoped for.⁽⁹⁾ The "prior questions" that block the shift include: socioeconomic issues of malnutrition and poverty, complicated by recurrent drought and famine; the increasing economic divide and the economic policies of wealthy nations, with globalisation and marginalisation; poor health infrastructure, referral systems, transport infrastructures; political priorities focused on issues other than health; civil unrest and war; the "brain drain", a virtual evacuation of skills; and the debilitating effects of foreign aid and foreign debt.

In many countries more money is spent on servicing debt than on health and education combined.^(2,99) On average 15% of the GDP of African states is in the form of foreign aid, yet the cost of servicing foreign debt is far more than aid received; economist Andrew Mwenda says foreign aid that is mostly in the form of budget support makes "government employment the best business opportunity", and stifles economic growth;(100) "Our governments seek profit through outside aid not through their own people." He appeals to the West to stop financial aid and rather help to empower individuals. Aid has indeed been rapidly reducing with the worldwide financial crisis, while the debt crisis worsens.

Partly to address these background issues, the "Millennium Development Goals" (MDGs) were agreed upon at the United Nations Millennium Summit in 2000, incorporating leaders from 191 nations, aiming to meet them by 2015.(101) Addressing children's heart disease is part of the context of goal number 4, to "reduce by two thirds the mortality rate among children under five." It is most unlikely that this will be achieved by 2015,(102,103) but any progress made will make paediatric heart disease increasingly important as a cause of morbidity and mortality. Progress would also free up health resources.

Alarmingly, the under-5 mortality in South Africa has actually increased,⁽¹⁰⁴⁾ even though there has been a small decrease in Africa as a whole over the first 8 years of the MDG process.⁽¹⁰⁴⁾

This context of extreme poverty and unmanageable burden of disease must be part of our consideration in seeking to develop cardiac care. However, if we can benefit children with cardiac disease using funds that would not otherwise be made available for the broader problems, then the overall healthcare infrastructure would surely benefit.

SOME SUGGESTED WAYS FORWARD

The task seems overwhelming, yet many organisations and individuals have taken up the challenge, and some progress has been made, albeit slow. Major reasons for slow progress are lack of funding and lack of cooperation (or lack of interest?) at local government levels to enable sustainability of a cardiac programme. Health expenditure is a large part of the GDP in developed nations, but only a small fraction in African countries,^(84,105) keeping most tertiary services out of reach. Many strategies have been tried to improve the situation, but the main question is: How can we accelerate progress? Here are some suggestions.

Work together

Those of us currently involved in paediatric cardiac care in Africa need to work together, coordinating our efforts to become as cost-efficient and appropriate as possible, seeking to be a pressure group that can attract attention and action from local governments as well as international groups. Efforts to help, especially from the developed world, need better coordination in partnership with Africans so as to avoid duplication of efforts and waste of resources. PASCAR is a potential forum for developing such cooperation, and discussions along these lines were begun at the PASCAR meeting in Nairobi in 2007. There are also many models of different approaches being tried that could become part of a larger coordinated effort to provide services for Africa, for example:

- Children's Heartlink is a USA-based NGO which has moved its focus from sending expensive missions to building local expertise. They are currently working in various centres in Africa, including at our unit in Cape Town, to support, train and develop local personnel in cost-effective ways. These include training/teaching missions of experts from first-world units, and twinning arrangements of African units with overseas units, with short-term staff exchanges. They have helped our unit to twin with Stanford University in California, and short-term staff exchanges have started.
- The Walter Sisulu Paediatric Cardiac Centre for Africa is an example of an NGO raising funds to utilise excess capacity in a private unit to facilitate surgery for indigent patients who otherwise would have no access to care.

- The Namibia Heart Project was initiated in 2007 following an intergovernmental agreement between Namibia and South Africa whereby the two governments would share the cost of developing a new cardiac service in Windhoek through a partnership with the University of Cape Town. Negotiations with other African governments are also ongoing.
- The Italian NGO Associazione Bambini Cardiopatici nel Mondo is currently building their third paediatric cardiac centre in Africa. They are working toward training local expertise in these centres in partnership with the UK-based Chain of Hope NGO.
- We have partnered with the French NGO La Chaine de L'Espoir in surgical missions to Mozambique, in the understanding that it is more efficient and cost-effective to use teams from a neighbouring country.

Interaction and mutual support could become a continent-wide network to share ideas and frustrations and help build a community that will promote, build, and sustain cardiac care. (see Figure 3.)

Build local infrastructure through teams

There is no point in training a surgeon who has no local infrastructure in which to work, yet this has been done many times, usually because the individual seeks out the training for him- or herself. There are in Africa trained cardiologists with no surgical support, and vice versa. A full support team is required for a cardiac service.⁽⁷³⁾ We know of a group who could not operate for lack of a perfusionist, so we trained one of the surgeons in perfusion technology, a relatively quick process. Equipment is vital too. We are trying to source a bypass pump for another group who cannot operate for lack of one.

The goal of training must be a complete local team that can sustain a programme. This requires coordination; training centres must liaise with administrations, preferably university centres where peer pressure and academic values will form strategies, and not with individuals. Training need not all be in one centre or even in one country, as long as the team strategy is in place.

Support from a local authority or university has proven important for success, as are strategic funding partners interested in building a local service.⁽⁸⁷⁾ A degree of education of the local community and recruitment of political leadership is important.

Paid fellowships in South Africa for Africans could help us if we are, as some say, training too many surgeons. Funding is commonly an issue for Africans seeking training.

An example of coordinated training is the Namibian Heart Project: we are training personnel in our unit at all levels, aimed at forming an autonomous team in Windhoek, whilst some key persons of the team are training at other units. A coordinated approach ensures there are no gaps to prevent the service being initiated and sustained.

Training partnerships with large units in developed countries are of benefit to both sides; visiting first-world personnel are exposed to pathology they seldom see.

Prevention

As has been mentioned, secondary prophylaxis of rheumatic fever is an important strategy for RHD.^(8,24,33,106) Many notable successes have been reported through prevention programmes with decreased prevalence, hospital morbidity and mortality; for example in Cuba, Costa Rica, Egypt, Martinique and Guadeloupe,^{(12,1660,61,107,} ^{108,109,110,111,112,113} and the development of the A.S.A.P. proposal holds similar promise in this regard for Africa.⁽⁸²⁾ Having said this, support and motivation for prevention would be strengthened in the context of a curative (surgical) programme, and the latter needs to be promoted for the sake of the millions who already have crippling RHD in Africa.

"You cannot have an effective prevention programme if you don't treat those affected by the disease today." – Daniel Sidi, Nov.3rd 2008, SAHA meeting.

Simplify detection, diagnosis and treatment

If we move away from the first-world approach of sophisticated technology helping with detailed anatomical diagnoses, it could open the door to more ready detection and diagnosis of basic cardiac lesions.⁽⁷⁴⁾ With the growing network of secondary or regional hospitals in Africa, there is place for echocardiography technologists using low-end cheaper machines to screen for common cardiac lesions, with the possibility of selective referral to regional centres for surgery. (Figure 4) In Nigeria, for example, the six state teaching hospitals that have hosted brief episodes of cardiac surgery through visiting teams are amongst 68 state and private general training hospitals, with an additional general referral hospital in every major city. Such vast infrastructures hold promise;



FIGURE 3: The population density of Africa suggests the positioning of regional surgical referral centres, and there are a few basic cardiac surgical services available. For many healthcare systems in Africa, Cardiac surgery is their first request.



Source: World Health Organisation. Regional Office for Africa. The health of the people: the African regional health report. 2006. http://www.afro.who.int/regionaldirector/african_regional_health_report2006.pdf

there is perhaps a place to begin with a simplified approach to surgical programmes, perhaps emulating the early years of cardiac surgery in the 1950s. Mobile diagnostic teams at the township level are already an emerging reality in South Africa. Mobile clinics with traveling technologists along the model of the "Save a child's heart" programme could channel children requiring specialist attention to referral centres, where today's transapical catheter technologies if radically simplified could be applied by trained local teams without surgical backup. The risk of no backup would be far outweighed by the lives saved.

Daniel Sidi, speaking at the 9th Annual Conference of the SA Heart Association last year, said of the multiple new secondary level hospitals: "They fear to practice any cardiac surgery while they already perform visceral and orthopaedic surgery."

Data and technology

The global expansion of cheap and improved communications technology, and the rapidly spreading access to internet even in remote areas holds much potential for training and sharing of ideas and advice. In many parts of Africa internet access is easier than telephone communications. In 2001 James Cox of the World Heart Foundation proposed the use of internet technology to share knowledge and promote education through live internet conferences, expert email consultations, and even making major journals available free of charge.⁽⁸⁶⁾

Some of his goals are coming to fruition. Some journals are offering free online access to back-issues. The first live teleconference of the World Heart Foundation was held late in 2008, focused on Vietnam and Asia, but open to all.⁽¹¹⁴⁾ Sophisticated teleconferencing equipment is being investigated by the South African Department of Health for installation at major centres around the country with a vision of building a national network. This could be spread to neighbouring countries at little extra cost. PASCAR could again be a useful facilitator.

Coordination of personnel data on a database of trained experts and even volunteers may be another useful tool in building local teams.

Appropriate research

There is a great deal of inappropriate and even unethical research going on in Africa, much of it driven by the needs of the developed world. There are university medical complexes without basic laboratory facilities who have an MRI scanner, because a foreign foundation needed it for a particular project. The medical community of Africa needs to take a stand on appropriateness of research and expenditure.

Simple documentation of epidemiology would be an suitable start as a route to pressuring funders. There is, for example, no good data on the incidence of acute rheumatic fever in Africa, and at one time it was thought not to be a significant problem.⁽²⁴⁾

Plugging the "brain drain"

The lack of appropriate remuneration is commonly considered the main reason for loss of skills from Africa, but there are many other important causes; lack of team support to enable cardiac surgery, lack of equipment, political uncertainty, poor career prospects, and pressure from the disease burden are some of them.^(2,4) Active recruitment by developed nations also contributes; the best trainees from Africa are lured away. South Africa, even our own institution, is part of this problem.

An example of the scope of the dilemma: the Malawi Medical School in Blantyre has funded 21 doctors for specialist paediatric training in developed nations over 10 years; 18 completed the training, but only one has returned to Malawi, in spite of various incentive programs.⁽¹¹⁶⁾

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Support groups need to address this. Institutions and governments need to be taken to task for the way they use personnel from developing nations to make up their own shortfalls.

Recommendations for international organisations

Apart from all the above discussion, international aid groups should also be encouraged to:

- Coordinate efforts between organisations and with local African efforts.
- Undertake advocacy for increased international assistance through government policies.
- Engage African governments on issues of health policy.
- Learn from one another; some NGOs have gone through a long learning curve and have much to teach on how to help Africa.

CONCLUSION

"Every observer of human misery among the poor reports that disease plays the leading role." – Irving Fisher (116)

There is a hidden epidemic of dying and disabled children in Africa. There is much that the world's cardiac practitioners could do to address the problem, and there seems to be a growing willingness in the cardiac community to do just that, but little coordination or agreement about strategy. It will take a lot of time and effort, and no small amount of sacrifice, to make any significant change.

As cardiac practitioners in Africa, we need to take a lead in directing and advising, in open collaboration with one another and with our colleagues throughout the continent and internationally. Children have a particularly raw deal with heart disease; the major ordeal of surgery has to be endured before they can even begin on the journey of life, and yet in our continent very few even have this option.

REFERENCES

- UN Human Development Program. Human Development Indices: A statistical update 2008. http://hdr.undp.org/en/media/HDI_2008_EN_Complete.pdf Accessed August 2009.
- 2. Logie DE, Benatar SR. Africa in the 21st century: can despair be turned to hope? BMJ 1997;315:1444-1446.
- 3 Oxfam.The Oxfam poverty report. Oxford: Oxfam, 1996.
- Children's HeartLink. Global Report on Pediatric Cardiac Disease Linked by a common purpose. 2007. http://www.childrensheartlink.org/documents/Global %20Report%205-17.pdf (accessed August 2009).
- 5. Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat (2009). World Population Prospects: The 2008 Revision. Highlights. New York: United Nations. http://www.un.org/esa/population/ publications/wpp2008/wpp2008_highlights.pdf Accessed August 2009.
- 6 UNICEF report: The State Of The World's Children 2009. http://www.unicef.org/ sowc09/report/report.php Accessed August 2009.
- 7. Thakur JS, Negi PC, Ahluwalia SK, et al. Integrated community-based screening for cardiovascular diseases of childhood. World Health Forum. 1997;18(1):24-7.
- 8 Oli K, Asmera J. Rheumatic heart disease in Ethiopia: Could it be more malignant? Ethiop Med | 2004:42:1-8.
- 9. A Mbewu. The burden of cardiovascular disease in sub-Saharan Africa. SA Heart lournal. 2009:6(1):4-10.
- 10. World Health Organisation: The World Health Report 2008. Geneva, Switzerland: World Health Organisation, 2008. http://www.who.int/whr/2008/en/index.html (accessed August 2009).
- 11. Bland EF, Jones TD. Rheumatic fever and rheumatic heart disease: a twenty-year report on 1,000 patients followed since childhood. Circulation 1951; 4: 836-43.
- 12. Majeed HA, Batnager S, Yousof AM, et al. Acute rheumatic fever and the evolution of rheumatic heart disease: a prospective 12 year follow-up report. J Clin Epidemiol 1992; 45:871-75.
- 13. Carapetis JR, Mayosi BM, Kaplan EL. Controlling rheumatic heart disease in developing countries. Cardiovasc | S Afr. 2006 Jul-Aug; 17(4): 164-5.
- 14. Carapetis JR, McDonald M, Wilson NJ. Acute rheumatic fever. Lancet. 2005 Jul 9-15:366(9480):155-68.
- 15. Massell BF, Chute CG, Walker AM, et al. Penicillin and the marked decrease in morbidity and mortality from rheumatic fever in the United States. N Engl J Med 1988:318:280-286.
- 16. World Health Organisation. 2001. Rheumatic fever and rheumatic heart disease. Report of a WHO Study Group. Geneva. WHO Tech Rep Ser. 2001; 923. http://www.who.int/cardiovascular_diseases/resources/trs923/en/ (accessed August 2009).
- 17. Gordis L, Lilienfeld A, Rodriguez R. Studies in the epidemiology and preventability of rheumatic fever, 2: socio-economic factors and the incidence of acute attacks. | Chron Dis 1969;21:655-66.
- 18. Ouinn RW. Comprehensive review of morbidity and mortality trends for rheumatic fever, streptococcal disease, and scarlet fever: the decline of rheumatic fever Rev Infect Dis 1989, 11, 928-53
- 19. Markowitz M. Pioneers and modern ideas: rheumatic fever a half-century perspective. Pediatrics 1998; 102: 272-74.
- 20. Gordis L. The virtual disappearance of rheumatic fever in the United States: Lessons in the rise and fall of disease. T. Duckett Jones memorial lecture. Circulation 1985:72:1155-1162
- 21. Munlos S. Present role and limitations of surgery in the treatment of rheumatic heart disease. Cardiologie tropicale, 1987, 13(52): 135-141.
- 22. Cohen Al, Tamir A, Houri S, et al. Save a child's heart: we can and we should. Ann Thorac Surg 2001; 71: 462-468.
- 23. Novick WM, Stidham GL, Karl TR, et al. Are we improving after 10 years of humanitarian paediatric cardiac assistance? Cardiol Young 2005;15: 379-384.

REFERENCES

- Manyemba J, Mayosi BM. Intramuscular penicillin is more effective than oral penicillin in secondary prevention of rheumatic fever - a systematic review. S Afr Med J 2003; 93: 212-218.
- 25. Markowitz M, Kaplan E. Reappearance of rheumatic fever. Advances in pediatrics, 1989, 36: 39-66.
- Steer AC, Adams J, Carlin J, et al. Rheumatic heart disease in school children in Samoa. Arch Dis Child. 1999 Oct;81(4):372.
- Tibazarwa KB, Volmink JA, Mayosi BM. Incidence of acute rheumatic fever in the world: a systematic review of population-based studies. Heart. 2008 Dec; 94(12):1534-40.
- Longo-Mbenza B, Bayekula M, Ngiyulu R, et al. Survey of rheumatic heart disease in school children of Kinshasa town. Int J Cardiol. 1998 Feb 28;63(3):287-94.
- McLaren MJ, Hawkins DM, Koornhof HJ, et al. Epidemiology of rheumatic heart disease in black school children of Soweto, Johannesburg, BMJ. 1975;3:474-478.
- Marijon E, Ou P, Celermajer DS, et al. Prevalence of rheumatic heart disease detected by echocardiographic screening. N Engl J Med. 2007 Aug 2;357(5): 470-6.
- Anabwani GM, Bonhoeffer P. Prevalence of heart disease in school children in rural Kenya using colour-flow echocardiography. East Afr. Med J 1996: 73:215-217.
- Agarwal BL. Rheumatic heart disease unabated in developing countries. Lancet 1981;2:910-911.
- Kumar R. Controlling rheumatic heart disease in developing countries. World health forum. 1995;16(1):47-51.
- Soler-Soler J, Galve E. Worldwide perspective of valve disease. Heart 2000;83: 721-725.
- Carapetis JR, Steer AC, Mulholland EK, et al. The global burden of group A streptococcal diseases. Lancet Infect Dis 2005;5:685-694.
- 36. Barlow JB. Aspects of active rheumatic carditis. Aust N Z J Med 1992;22:592-600.
- Marcus RH, Sareli P, Pocock WA, et al. The spectrum of severe rheumatic mitral valve disease in a developing country. Correlations among clinical presentation, surgical pathologic findings, and hemodynamic sequelae. Ann Intern Med 1994;120:177-183.
- Carapetis JR, Currie BJ. Mortality due to acute rheumatic fever and rheumatic heart disease in the Northern Territory: a preventable cause of death in aboriginal people. Aust N Z J Public Health 1999;23:159-163.
- Roy SB, Bhatia ML, Lazaro EJ, et al. Juvenile Mitral Stenosis in India. Lancet 1963;41:1193-1195.
- Joshi MK, Kandoth PW, Barve RJ, et al. Rheumatic fever: Clinical profile of 339 cases with long term follow up. Indian Pediatr 1983;20:849-853.
- Joswig BC, Glover MU, Handler JB, Warren SE, Vieweg WV. Contrasting progression of mitral stenosis in Malayans versus American-born Caucasians. Am Heart J. 1982 Dec; 104(6):1400-3.
- Rammelkamp CH. Rheumatic heart disease a challenge. Circulation 1958;17: 842-51.
- Wood HF, Stollerman GH, Feinstein AR, et al. A controlled study of three methods of prophylaxis against streptococcal infection in a population of rheumatic children. N Engl J Med 1957;257:394-8.
- Taranta A, Wood HF, Feinstein AR, et al. Rheumatic fever in children and adolescents. IV. Relation of rheumatic fever recurrence rate per streptococcal infection to the titres of streptococcal antibodies. Ann Intern Med 1964;60 (Suppl 5):47-57.
- Denny FW. T. Duckett Jones and rheumatic fever in 1986. T. Duckett Jones Memorial Lecture. Circulation 1987;76:963-70.
- Markowitz M. Observations on the epidemiology and preventability of rheumatic fever in developing countries. Clin Ther 1981;4:240-251.
- Land MA, Bisno AL. Acute rheumatic fever. A vanishing disease in suburbia. JAMA 1983;249:895-8.

- Fraser GE. A review of the epidemiology and prevention of rheumatic heart disease: Part II. Features and epidemiology of streptococci. Cardiovasc Rev Rep 1996;17:7-23.
- Carapetis JR, Currie BJ, Mathews JD. Cumulative incidence of rheumatic fever in an endemic region: a guide to the susceptibility of the population? Epidemiol Infect 2000;124:239-44.
- Essop MR, Wisenbaugh T, Sareli P. Evidence against a myocardial factor as the cause of left ventricular dilation in active rheumatic carditis. J Am Coll Cardiol 1993;22:826-9.
- 51. Tani LY. Rheumatic fever and rheumatic heart disease. In: Moss and Adams' heart disease in infants, children, and adolescents: Including the fetus and young adults, 7th Edition, Volume Two. Eds: Allen HD, Driscoll DJ, Shaddy RE, Feltes TF. Lippincott Williams & Wilkins, 2008.
- Jaiyesimi F. Chronic rheumatic heart disease in childhood: its cost and economic implications. Tropical Cardiology, 1982;8(30):55-59.
- Kimbally-Kaky G, Makoumbou P, Nzingoula S. Acute rheumatic fever among children in the Republic of Congo: report of 56 cases. Dakar Med, 2002;47:57-9.
- Meira ZM, Goulart EM, Colosimo EA, et al. Long term follow up of rheumatic fever and predictors of severe rheumatic valvar disease in Brazilian children and adolescents. Heart. 2005 Aug;91(8):1019-22.
- 55. Olubodun JOB. Acute rheumatic fever in Africa. Africa Health, 1994;16(5):32-33.
- Ekra A, Bertrand E. Rheumatic heart disease in Africa. World Health Forum, 1992; 13(4):331-333.
- Terreri MT et al. Resource utilisation and cost of rheumatic fever. Journal of Rheumatology, 2001;28(6):1394-1397.
- Githang'a D. Rheumatic heart disease (editorial comment). East African Medical Journal, 1999;76(11):599-600.
- World Health Organisation. Rheumatic fever and rheumatic heart disease. Report of a WHO Study Group. Geneva, World Health Organisation, 1988 (Technical Report Series, No. 764).
- World Health Organisation. Joint WHO/ISFC meeting on RF/RHD control with emphasis on primary prevention, Geneva, 7-9 September 1994. (document WHO/CVD 94.1).
- World Health Organisation. The WHO Global Programme for the prevention of RF/RHD. Report of a consultation to review progress and develop future activities. 2000. (WHO document WHO/CVD/00.1).
- Bertrand E.The burden of the rheumatic heart disease in Africa. What could be done? Cardiologie Tropicale, 1987;13(49):7-8.
- Kaplan E, et al. Understanding group A streptococcal infections in the 1990s: Proceedings of a symposium. Pediatric Infectious Disease Journal, 1994;13: 556-583.
- el Kady AA, Saleh S, Gadalla S, et al. Obstetric deaths in Menoufia Governorate, Egypt. Br J Obstet Gynaecol 1989;96:9-14.
- Anonymous. A review of maternal deaths in South Africa during 1998. National committee on confidential enquiries into maternal deaths. S Afr Med J 2000; 90:367-73.
- World Health Organisation. Rheumatic fever and rheumatic heart disease. World Health Organ Tech Rep Ser 2004;923:1-122.
- Koegelenberg CF, Doubell AF, Orth H, et al. Infective endocarditis in the Western Cape Province of South Africa: a three-year prospective study. Qjm 2003;96: 217-25.
- World Health Organisation. The current evidence for the burden of group A streptococcal diseases. http://whqlibdoc.who.int/hq/2005/WHO_FCH_CAH_ 05.07.pdf (Accessed August 2009).
- Ifere OA, Masokano KA. Infective endocarditis in children in the Guinea savannah of Nigeria. Ann Trop Paediatr 1991;11:233-40.

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- 70. Bennis A, Zahraoui M, Azzouzi L, et al. Bacterial endocarditis in Morocco. Ann Cardiol Angeiol (Paris), 1995;44:339-44.
- Vaidyanathan, B, Kumar, R.K. 2005. The global burden of congenital heart disease. Congenital Cardiology Today. 3(10): 1-8.
- Hoffman JIE, Kaplan S.The incidence of congenital heart disease. J Am Coll Cardiol 2002;39:1890-900.
- Leblanc JG. Creating a global climate for pediatric cardiac care. World J Pediatr, Vol 5 No 2. May 15, 2009.
- Abdulla R. Congenital heart disease management in developing countries. Pediatr Cardiol 2002;23:481-482.
- British Heart Foundation Statistics Website. http://www.heartstats.org/datapage. asp?id=3395 Accessed August 2009.
- Webb G, Williams R. 32nd Bethesda Conference: Care of the adult with congenital heart disease. Journal of the American College of Cardiology. 2001; 37:1161-98.
- Children's HeartLink. Global report on pediatric cardiac disease to save a child: we can do more to address global trends in pediatric heart disease.
 2005. http://www.childrensheartlink.org/documents/ChildrensHeartlinkStudy.pdf Accessed August 2009.
- Christianson A, Howson CP, Modell B (2006). March of Dimes global report on birth defects: the hidden toll of dying and disabled children. Research report. 2006. March of Dimes Birth Defects Foundation, White Plains, USA. http://www. marchofdimes.com/MOD-Report-PF.pdf. Accessed August 2009.
- McLaren MJ, Markowitz M, Gerber MA. Rheumatic heart disease in developing countries: the consequence of inadequate prevention. Ann Intern Med 1994;120:243-5.
- Rheumatic fever in children and adolescents. A long-term epidemiologic study of subsequent prophylaxis, streptococcal infections, and clinical sequelae. HF Wood, AR Feinstein, A Taranta, JA Epstein, R Simpson. 1964;60:2(Pt 2),31-46.
- Jose VJ, Giomathi M. Declining prevalence of rheumatic heart disease in rural schoolchildren in India. Indian Heart J 2003;55:158-160.
- Robertson KA, Volmink JA, Mayosi BM. Towards a uniform plan for the control of rheumatic fever and rheumatic heart disease in Africa – the Awareness Surveillance Advocacy Prevention (A.S.A.P.) Programme. S Afr Med J. 2006 Mar;96(3Pt 2):241.
- World Health Organisation. Declaration of Alma Ata. International conference on primary health care, Alma-Ata, USSR, 6-12 September 1978. Geneva: WHO, 1978. www.who.int/hpr/NPH/docs/declaration_almaata.pdf. Accesed August 2009.
- Hewitson J, Brink J, Zilla P. The challenge of pediatric cardiac services in the developing world. Semin Thorac Cardiovasc Surg 2002;14:340-345.
- Pezzella AT. Open heart surgery in a developing country. Asian Cardiovasc Thorac Ann. 2006 Aug; 14(4):355-6.
- Cox JL. Presidential address: changing boundaries. J Thorac Cardiovasc Surg. 2001 Sep;122(3):413-8.
- Novick WM, Stidham GL, Karl TR, et al. Paediatric cardiac assistance in developing and transitional countries: the impact of a fourteen year effort. Cardiol Young. 2008 Jun;18(3):316-23.
- Buchanan-Lee B, Levetan BN, Lombard CJ, et al. Fixed-dose versus adjusted-dose Warfarin in patients with prosthetic heart valves in a peri-urban impoverished population. J Heart Valve Dis 2002;11:583-592.
- Eze JC, Ezemba N. Open-heart surgery in Nigeria: indications and challenges. Tex Heart Inst J. 2007;34(1):8-10.
- 90. Personal communication, PASCAR conference, Nairobi, May 2007.
- 91. Personal communication, local physicians in Lusaka, Zambia.
- 92. Unpublished data: Survey by the Paediatric Cardiac Society of South Africa. 2006.
- From presentations and personal interactions at the Pan African Society of Cardiology meeting in Nairobi, May 2007.

- Yonga, G.O and Bonhoeffer P. Percutaneous transvenous mitral commissurotomy in juvenile mitral stenosis. E. Afr. Med. J. 2003;80:172-174.
- Zilla P, Brink J, Human P, et al. Prosthetic heart valves: catering for the few. Biomaterials. 2008 Feb;29(4):385-406.
- Logan A. The first trans-ventricular mitral valvulotomy at Edinburgh in 1954. Indian Journal of Thoracic and Cardiovascular Surgery, 1984;3:54-55.
- Logan A, Turner R. Surgical treatment of mitral stenosis, with particular reference to the transventricular approach with a mechanical dilator. Lancet. 1959 Nov 21;2(7108):874-80.
- Tubbs OS. The Tubbs' Dilator. Indian Journal of Thoracic and Cardiovascular Surgery, 1987-88;5:47.
- Tangri R, Mwenda A. Corruption and cronyism in Uganda's privatisation in the 1990s. African Affairs 2001;100:117-133.
- Andrew Mwenda. Foreign aid and the weakening of democratic accountability in Uganda. Cato Institute, Washington. Foreign Policy Briefing no. 88. July 12, 2006.
- United Nations. Millenium development goals: UN Millenium Declaration. 2000. http://www.un.org/millenniumgoals/ Accessed August 2009.
- Lawn JE, Costello A, Mwansambo C, et al. Countdown to 2015: will the Millennium Development Goal for child survival be met? Arch. Dis. Child. 2007;92;551-556.
- 103. Statistics Division of the UN Department of Economic and Social Affairs. The Millennium Development Goals Report 2008. http://mdgs.un.org/unsd/mdg/Host. aspx?Content=Products/ProgressReports.htm. Accessed August 2009.
- 104. World Health Organisation Statistical Information System. Mortality Country Fact Sheet: South Africa. 2006. http://www.who.int/whosis/mort/profiles/mort_afro_ zaf_southafrica.pdf. Accessed August 2009.
- 105. Pezzella AT. International cardiac surgery: a global perspective. Semin Thorac Cardiovasc Surg 2002;14:298-320.
- 106. HF Wood, AR Feinstein, A Taranta, et al. Rheumatic fever in children and adolescents. A long-term epidemiologic study of subsequent prophylaxis, streptococcal infections, and clinical sequelae. 1964;60:2(Pt 2),31-46.
- 107. Nordet P, et al. Fiebre reumatica in Ciudad de la Habana. Prevalencia y caracteristicas, 1972–1987. [Rheumatic fever in Havana. Prevalence and characteristics, 1972–1987.] Revista Cubana Pediatria, [Cuban Journal of Pediatrics,] 1989;61(2):228-237.
- Arguedas A, Mohs E. Prevention of rheumatic fever in Costa Rica. Journal of Pediatrics, 1992;121(4):569-572.
- 109. Strasser T, et al. The community control of rheumatic fever and rheumatic heart disease: report of a WHO international cooperative project. Bulletin of the World Health Organisation, 1981;59(2):285-294.
- 110. Bach JF, et al. Ten-year educational programme aimed at rheumatic fever in two French Caribbean islands. The Lancet, 1996;347:644-648.
- 111. Neilson G, et al. Rheumatic fever and chronic rheumatic heart disease in Yarrabah aboriginal community, North Queensland. Establishment of a prophylactic program. Medical Journal of Australia, 1993;158:316-318.
- 112. Bitar FF, et al. Rheumatic fever in children: a 15-year experience in a developing country. Pediatric Cardiology, 2000;21(2):119-122.
- 113. Taranta A, Markowitz M. Rheumatic fever. Boston, Kluwer Academic Publishers, 1989:1-18.
- 114. Reported at http://www.world-heart.org/doc/11106.
- I 15. Personal communication: Dr. Robin Broadhead, Dean of Medicine, Blantyre.
- 116. Irving Fisher: National Conservation Commission. Report on national vitality, its wastes and conservation. 1909, p. 124. Washington, DC: US Government Printing Office.