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## **Establishing Pediatric Cardiovascular Services in the Developing World: A Wake-Up Call**

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## Establishing Pediatric Cardiovascular Services in the Developing World

### A Wake-Up Call

Magdi H. Yacoub, FRS

There is increasing realization that the lack of facilities for sustainable pediatric cardiac services in the developing world results in a massive number of preventable deaths and suffering. It is estimated that 15 million children die or are crippled annually by potentially treatable or preventable cardiac diseases. Ignored for a long time, this issue is starting to be a cause of major concern to individuals, governments, and, most importantly, cardiovascular specialists who can appreciate the gravity of the problem and that the current situation is unacceptable. What then can be done to alleviate the problem, by whom, and how? In this issue of *Circulation*, Larrazabal et al describe the pioneering efforts of Castenada and his colleagues in Guatemala.<sup>1</sup> This should act as a model and a source of inspiration in this field. This editorial is an attempt to outline some of the issues that relate to the problem, such as estimates of its size, and explores potential, long-lasting solutions.

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#### Size of the Problem

The pediatric population constitutes a larger proportion of the community in developing countries, with  $\approx 40\%$  of individuals <18 years old in some countries. Children in developing countries have a significantly higher incidence and prevalence of serious cardiac diseases.<sup>2</sup> This is contributed to by a variety of factors that include a lack of early correction of congenital cardiac abnormalities that results in accumulation of a large number of children with uncorrected anomalies who survive the neonatal period. In addition, many of these children develop more rapid deterioration in their clinical condition as a result of accelerated forms of secondary changes in the heart and other organs, such as pulmonary hypertension. Some of these changes could be the result of genetic and/or environmental factors such as pollution or infection. Furthermore, endemic “neglected” cardiac diseases such as rheumatic heart disease,<sup>3</sup> Chagas disease,<sup>4</sup> and endomyocardial fibrosis (EMF)<sup>5</sup> affect a very large number of children. It is estimated that 15.6 million people (mostly

children) suffer from rheumatic heart disease worldwide,<sup>3</sup> and that 470 000 new cases of rheumatic fever and 233 000 deaths caused by rheumatic fever or rheumatic heart disease occur each year.<sup>5</sup> In addition, the World Health Organization (WHO) estimated that 16 to 18 million people are currently infected with Chagas disease, with 90 million individuals at risk of infection.<sup>6</sup> The disease has been classified as one of the most neglected diseases in the world.<sup>7</sup> Recent studies of EMF in endemic areas of Mozambique have shown a prevalence of 18% of the population, and again children are predominantly affected (A.O. Mocumbi, MD, unpublished data, 2007).

In industrialized countries, the need to create and fund pediatric units is related to national need. A panel convened by the WHO to advise about optimal resources for pediatric cardiac services concluded that a center able to perform 300 to 500 pediatric operations annually is needed in developed countries for populations of 2 million people. No accurate statistics are available about the need for pediatric services in the developing world. This number, however, is likely to be much greater than that required in developed countries—probably on the order of 1 center per million people. The sobering fact, however, is that many countries with populations between 15 and 70 million people are without a single specialized pediatric cardiac center able to offer modern preventive and therapeutic procedures.

#### Major Players and Stakeholders

The creation of high-quality, sustainable centers requires intensive coordinated efforts by several groups who need to be involved from the beginning. Cardiovascular specialists can and should play a major part throughout all the stages. Professionals can work most effectively through establishment of nongovernmental organizations (NGOs) dedicated to this cause and the involvement of all parts of the specialty, which include administration, nursing, anesthesia, and other areas of expertise from the community such as lawyers, bankers, and business people. The NGOs can work closely with other similar organizations as well as national and international bodies such as the WHO, World Heart Federation, World Bank, United Nations, Millennium Fund, PVRI (Pulmonary Vascular Research Institute), and others. In the country where the project is envisioned, the first step is to establish connections with local professionals, opinion leaders, universities, and the government as well as insurers if they exist. Initially this could be in the form of enabling projects and later as full partners.

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### Enabling Projects

It is important to highlight the pressing need, explore the local scene, and heighten awareness. This can be done through “enabling projects,” which can consist of establishing contact between the NGOs and the local professionals with the explicit aim to establish and/or strengthen diagnostic units run by local colleagues who can act as correspondents and a nucleus for the future sustainable center while establishing contact with the major players outlined above. Transportation of children for treatment in the donor countries, coupled with “missions” to existing nonspecialist hospitals can act as enabling projects and help bring the problems into focus while the definitive answer of the creation of a sustainable unit is planned. Apart from their humanitarian value, the missions should concentrate on training of professionals, identification of potential candidates for further training, and exploration of the possibilities regarding the ultimate sustainable centers.

### Building Infrastructure

The infrastructure needed includes buildings, equipment, and most importantly human resource. The buildings can be modeled on existing facilities in developed countries but adapted to local culture, environment, and needs. The equipment should include state of the art tools to offer services at the highest level.

Buildup of human resources can be a lengthy and difficult process and requires a coordinated effort through the establishment of a board for higher training in the required subspecialties. The board can act in collaboration with the stakeholders to recruit, train, and accredit individuals identified for their suitability for further training, which can be performed mainly locally through systems of missions and mentoring supplemented by funding scholarships to specific institutions for specific reasons. Continuing education programs coupled with audits of individual performances should be an integral part of the training programs. The value of the establishment of appropriate management structures for the evolving centers cannot be overemphasized.

### Sustainability

The ultimate fate and impact of the center depends almost entirely on sustainability, which therefore must constitute a major part of the initial and ongoing planning. One of the most important points to consider is allocation of sufficient funds to run the centers with contributions from all the partners, including the local government, insurance companies, and capable members of the community, regardless of how small those contributions are initially. Ongoing negotiations that depend on the success of the center can shift the responsibility (by design) to the local sources. Another important source of funding for the pediatric activity is from inclusion of a certain number of adult services, which can help substantially with training of personnel. The second important consideration to ensure sustainability is staff retention. This can be helped by creation of good working conditions, material compensation, and, importantly, inclusion of programs for postgraduate training and facilities for research to enhance professional and academic satisfaction.



**Figure.** A research team investigates the prevalence of EMF in an endemic area in Mozambique. A, Carrying equipment to the research site. B, Investigating children in their own home in rural endemic areas of Mozambique.

### Role of Research

One of the main components of the envisioned, sustainable pediatric centers is research. Apart from provision of a means to audit the clinical service and help to achieve excellence, research provides important means to define the size of local problems, such as neglected diseases, and helps the evolution of appropriate solutions by the local researchers. The infrastructure and management of research can be provided initially by the partners from the developed country as exemplified in the article by Larrazabal et al and the Mozambique EMF project. The research programs should include audits of high-tech medicine, epidemiology, and, importantly, molecular and cellular laboratories.<sup>8–11</sup> The latter can be devoted to research into the local neglected diseases at fundamental levels and eventually into biotechnology,<sup>12</sup> which can generate income while the profile of both the center and the morale of the researchers are markedly enhanced. In addition, it could have a positive effect on other areas of health care. One example of research into a neglected disease is the establishment of a research center in Mozambique devoted to the study of EMF at population, clinical, and molecular levels. This has been enthusiastically received by both the researchers and the population. The Figure shows the

research team, which includes 1 of the principle investigators, and other members, which include a research assistant, a community leader, and 2 helpers. Further intensive efforts into research and development similar to those adopted in developed countries<sup>13</sup> could yield considerable benefits<sup>14,15</sup> for all concerned with the generation of new knowledge that could be applicable to diseases in the developed world.

### Conclusions and Future Directions

Establishment of specialized pediatric cardiac centers is evolving as an achievable priority target. The aim is to establish a network of centers of excellence that include research and contribute both locally and globally. The success of these projects depends on collaborative efforts by all concerned. The envisioned results fully justify the effort.

### Disclosures

None.

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