

Birth of a New Program in Mexico City: The Kardias Experience

Alexis Palacios-Macedo

In the last two decades there has been huge progress and technological development in congenital heart surgery. Children with congenital heart disease in the first-world countries have the opportunity of being diagnosed and treated with a very high quality of medical and surgical attention. Third-world countries have much less to offer to these patients. Several attempts have been made to alleviate this reality. Foundations created in developed countries have played a major role. We believe, however, that promoting the development of local foundations in the countries in need could be even more helpful because local physicians can participate actively in coordinating the actions needed. Through our foundation, Kardias, we have been able to achieve significant improvements in the quality of care at the Instituto Nacional de Pediatría in Mexico City.

Semin Thorac Cardiovasc Surg Pediatr Card Surg Ann 11:7-10 © 2008 Elsevier Inc. All rights reserved.

KEYWORDS Foundation, philanthropy, underdeveloped societies

The vast majority of congenital heart diseases, even the most complex, can now be corrected or undergo some type of palliation that will allow, in most cases, a healthy life for the patient. In the last two decades mortality in many centers of the world has come down in an impressive way. However, this is only true for developed societies. Many children born with congenital heart malformations in developing countries continue to lack proper and timely diagnosis and treatment. Only about 30% of all heart malformations in the world are actually diagnosed. Therefore, many children still die without even being diagnosed.¹

Although not performed exclusively for pediatric cardiac surgery centers, the results of a worldwide survey made and published a few years ago help to illustrate the dramatic and uneven way in which cardiac surgery centers are distributed throughout the world. In North America, each cardiac surgery center serves approximately 120,000 persons; in Europe, around 1,000,000; in Asia, 16,000,000; and in Africa, 33,000,000. This translates to 1,222 surgeries performed annually per million population in North America, 789 surgeries in Australia, 569 in Europe, 147 in South America, 37 in

Russia, 25 in Asia, and only 16 in Africa, with a mean for the whole world of 169.²

As Dr. James Cox stated in his presidential address at the American Association for Thoracic Surgery meeting a few years ago, 93% of patients living outside North America, Australia, and Europe have no access to cardiac surgery.³ For the pediatric population, currently approximately 5 million children (mainly in poor countries) are in desperate need for heart surgery and most of them will never have it.⁴

Approximately 70 charity organizations in the world have tried to help alleviate the suffering of these patients using a variety of strategies. Some have directed their efforts on transporting patients to more advanced health care systems to receive medical care. Although, without question generous, these programs face the following issues⁵:

- 1) They become very expensive, because in spite of the fact that no salaries are paid and many donated surgical products can be utilized, the cost of each surgery usually goes from 10 to 30 thousand dollars.
- 2) Medical attention is given to a very small proportion of children with heart disease.
- 3) Patients go back to their places of origin and cannot have an adequate treatment and follow-up.

An alternative approach has involved "medical mission" teams that provide surgical and postoperative care for a pre-identified group of patients needing attention. Depending on the destination and length of the trip, costs range from 15 to

Division of Congenital Heart Surgery, Instituto Nacional de Pediatría, Mexico City.

Address correspondence to Alexis Palacios-Macedo, MD, Insurgentes Sur 3700-C, Col. Insurgentes Cuicuilco, Mexico D.F. 04530; e-mail: alexispalaciosmacedo@yahoo.com

50 thousand dollars, and during a 10-day mission anywhere from 15 to 40 cases can usually be performed. Again, the high cost of such trips and the limited impact on the population in need presents a limitation.⁶⁻⁸

However, we as well as others believe that the greatest impact can be made by promoting the growth of congenital heart surgery programs in developing countries through collaborative efforts with established programs in developed countries that can provide continuous educational support and the “know how.” The World Heart Foundation has made a great effort in coordinating this kind of approach.⁹ Although initially also expensive, these initiatives eventually contribute tremendously to the development of pediatric heart surgery in emerging economies and set the basis for solid programs that can finally achieve standards close to those set in other countries.

Most of these organizations have been created in rich nations to help countries in need. I am convinced, however, that fostering more foundations in developing countries can be even more helpful. This is based on the fact that, without question, surgeons and other physicians know better than anyone else the real needs and the way to overcome problems they face in their own country. In their own environment, they can coordinate the help that tertiary centers and other organizations can offer.

This is the strategy that I have favored at the Instituto Nacional de Pediatría in Mexico City, creating Kardias,¹⁰ a nonprofit foundation dedicated exclusively to support the development of our Congenital Heart Surgery Department as well as the needs of its patients and their families.

Each country has its own health system, degree of poverty, and very specific local problems. Therefore, I do not think there is a single model that can be applied to every society. Our model is only an alternative, but one that has resulted in very satisfying changes in our hospital, with relatively low resources.

In Mexico, each year approximately 28,000 babies are born with a heart defect. Too many still die before having access to medical care, waiting for surgery on a long waiting list, or after surgery due to complications. The reasons for this are complex, as they are in most developing societies, but we can probably mention the following as the primary reasons: 1) economical limitations; 2) insufficient training of physicians and nurses; and 3) the bureaucracy in a system where most health care is provided by the government.

Why are There Economic Limitations?

Like many other emerging countries, Mexico is full of contrasts, with a deep inequality in wealth distribution. In spite of significant and impressive progress in some social and economical areas that place us in the countries considered to have a high human developmental index,¹¹ an index that evaluates life expectancy, literacy, education, and standard of living, there are still many problems. Of our total population of 106 million, 60% live in poverty, and 12% in extreme

poverty, that is, live with one dollar a day. Although medical attention is considered a right, only 6% of the Gross Domestic Product (GDP) is used by the State for health care. This is in contrast with the more than 15% that is used in developed countries. In addition, if we consider that the GDP in these countries is much higher than in Mexico, the difference in the total amount of resources dedicated to health care is enormous.

Therefore, it is with a limited budget that most people in Mexico receive medical attention, 60% at the social security hospitals and 37% on government welfare hospitals, both highly bureaucratic systems. Only 3% of the population has private medical insurance.

Why is Training of Physicians and Nurses Insufficient?

Because the great majority of congenital heart disease practice is mainly conducted in public hospitals, economic remuneration cannot be expected to be a motivating factor. It is not easy for a physician to be eager to work in a complex and stressful field where commitment is mandatory, when the average salary in a government hospital is \$20,000 dollars a year. Unfortunately, therefore, physicians involved in congenital heart surgery often seek economic remuneration in other medical activities that distract their attention from this field. Motivation needs to be found in the beauty of the work, and in the academic and intellectual development that comes as a consequence. But this motivation is not easy for everyone to find.

And finally, perhaps the biggest obstacle, the bureaucratic system. Congenital heart surgery is just one of many health care areas of a system drowned by many other needs. It is not expected to be a priority when many children still die, for example, of infectious diseases and malnourishment.

But, of course, children with heart diseases are not responsible for these problems . . .

I had the privilege of having been trained under the mentorship of Dr. Charles Fraser at a time when he was starting to lead the many changes that have positioned the Texas Children’s Hospital (Houston, TX) as one of the finest congenital heart surgery centers in the world.

Going back to Mexico as chief of congenital heart surgery at my institute, I had, as the biggest challenge, to set the conditions necessary to replicate, as close as I could, and with the limited resources and problems I knew I would face, the model for congenital heart surgery that I had learned that, unquestionably, was the right one.

In Mexico, although heart surgery began in the late 1950s, results for congenital heart surgery were still far from being optimal, especially for complex malformations.

The task was, of course, not easy. The bar was set very high. I realized at that time that perhaps the only way to overcome, at least partially, all these problems, was the creation of a foundation. A few years later, talking with Dr. Aldo Castañeda, who is working now in Guatemala, he agreed with this concept. Dr. Castañeda has also created a system

based on a local foundation, which has produced extraordinary results in a very short period of time, in a country where cardiac surgery was almost nonexistent before.

Kardias is a nonprofit organization, independent from our hospital and the government. It is a small but highly efficient foundation. Only six people work for the foundation in a permanent way. There are no salaries and only scarce administrative expenses. Therefore, all the resources are completely used for helping the families in need and promoting the development of our own Cardiac Surgery and Cardiology departments. Fundraising has mainly taken place in Mexico, although not exclusively, and we have tried to use a proven health care model, like the one at Texas Children's Hospital, adapted to our environment.

Our hospital is a 240-bed general pediatric hospital with all subspecialties. More than half of the patients we treat come from outside Mexico City, most from very low income families, and, so, most of the budget is funded by the government. Resources that can be used for our department, are, therefore, limited. Although our annual cardiology patient consult number is high, we can only perform, because of limitations in physical space and resources, approximately 150 cases a year.

Back in 2001, when we started to change our program, we found insufficient training for health professionals, old or inexistent equipment, no funds for prostheses or expensive drugs, no physical area for CVICU, no team work, bureaucracy, a very long waiting list for patients, and no complex cases were conducted because of the high mortality.

Our first action was to acquire the minimum necessary equipment. We purchased a transfer monitor, two high-tech ventilators, and a blood gas analyzer for the operating room, and we began providing patients with the necessary funds for expensive items like conduits and valves. However, we needed to look much farther ahead. Because we are part of the government health system, we decided to contact our health authorities and to make a strong alliance with them. We would provide constant fundraising for the cause, while they would facilitate as much as they could our work. Although they were not aware of specific problems that only us, the ones directly involved in the field were, they were willing to hear and to help.

To begin with, we offered to obtain the necessary funds to buy the equipment for a four-bed CVICU, while the government would provide 42 new positions for medical and nursing staff to work exclusively at our unit. Our team is now composed of two surgeons, three cardiovascular anesthesiologists, four intensivists, two psychologists, one social worker, four perfusionists, and 24 nurses (all dedicated exclusively to cardiovascular surgery), as well as one cardiologist, apart from the cardiology department, that evaluates and follows our surgical patients.

We now have access to more refined diagnostic tools, like transesophageal echocardiography (TEE), and, with the constant improvement in results, we can focus on improving our surgical monitoring with devices like the near infrared spectroscopy monitor (NIRS). And our intensive care unit is in the process of being built.

However, we needed something perhaps even more important, a continuous education program for our staff. With the invaluable help of the Congenital Heart Surgery and Cardiology Departments at Texas Children's Hospital, and with the sponsorship of an American philanthropist, we have just started a continuous academic exchange for our team to be trained at Texas Children's Hospital. Nurses, staff physicians, perfusionists, and residents are now trained for variable periods of time.

So, what has been the main impact of our politics since we started the program? In the year 2000, only 8% of the cases performed were complex. This increased to almost 40% in 2007. However, more importantly, mortality in this group of complex cases dropped from almost 100% to 20%. We now accept cases that were not done before, diseases from which, at our hospital, patients invariably died, and our global mortality has slowly decreased. It is important to notice, however, that our proportion of complex cases is lower than it is in other centers, not because we cannot or do not want to do them but because patients die before getting to us, and therefore, although we are optimistic about these numbers, we know that there is still much work to be done, particularly in promoting the early diagnosis and referral of patients from distant hospitals.

We have, without question, made some progress. However, we have not yet reached our goal. We still need to get closer to the standards set in the more advanced societies. We count on a group of good willing and committed people and the constant help of our foundation and benefactors.

It is important to realize, finally, that the reality of most societies in the world is quite different to what happens in developed economies, and what we learn from what is published in the most prestigious surgical journals cannot always be applied as we would wish. For example, treatment of a patent ductus arteriosus (PDA) can sometimes be a more challenging experience, as when associated with endocarditis, closure of ventricular septal defects, or other high pulmonary flow defects in teenagers or even adults is quite common, and cyanotic teenagers seen for the first time in the clinic is also not uncommon. Heart transplantation programs cannot be applied in a complete way when the cost of a ventricular assist device is unaffordable, and we must decide if it is ethically justifiable, for example, to treat as a priority in a system where a high proportion of patients can never undergo surgery, hypoplastic left heart syndrome instead of, for example, a ventricular septal defect.

Therefore, it is important to adapt our knowledge to our social reality. But, on the other hand, we know that the only way to progress is to try to push our limits as far as possible. Doing the most complex cases necessarily brings to the whole team the required expertise to handle the less difficult situations.

It is also vital to analyze our outcomes, to be truly honest, and to recognize and study our errors instead of hiding them. This is the only way we can make the necessary changes and excel in the field.

Conclusion

At present, there is a tremendous disparity in the way cardiac surgery care is provided in the world. Most children born with a cardiac defect will die before even having access to surgery. The creation of cooperation bonds between the most advanced centers in the world and the ones in developing countries seem to be the best way to go.

One way to achieve this is for local physicians to foster these exchanges, creating local foundations that could work hand in hand with other tertiary centers.

References

1. Abdulla R: Congenital heart disease management in developing countries. *Pediatr Cardiol* 23:481-482, 2002
2. Unger F: Worldwide survey on coronary interventions 1995. Report of the European Heart Academy of Sciences and ARTS. *Cor Europaeum* 7:128-146, 1999
3. Cox J: Presidential address: Changing boundaries. *J Thorac Cardiovasc Surg* 122:413-418, 2001
4. Kalangos A: Hearts for All. Presidential Address. Geneva, Switzerland. Global Forum on Humanitarian Medicare in Cardiology and Cardiac Surgery, May, 2003.
5. Heart Gift Foundation: Available at www.heartgift.org
6. Haitian Hearts: Available at: www.haitianhearts.org
7. Novick WM, Stidham GL, Karl TR, et al: Are we improving after 10 years of Humanitarian paediatric cardiac assistance? *Cardiol Young* 15:379-384, 2005
8. Children's Heartlink: Available at www.childrensheartlink.org
9. Washington Health Foundation: Available at www.whf.org
10. Kardias Foundation: Available at: www.kardias.org
11. Davies A, Quinlivan G: A panel data analysis of the impact of trade on human development. *J Socioeconomics* 35:868-876, 2006