

Delivering pediatric cardiac care with limited resources

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The idea of Annals of Pediatric Cardiology was conceived in 2007. The journal was brought out because it was felt that pediatric cardiac professionals from India and other parts of the developing world needed an accessible medium for exchange of ideas and information. The available mainstream journals that published material on pediatric heart care largely served the needs of professionals from advanced nations with somewhat disproportionate representation from selected leading institutions endowed with abundant human and material resources. This resulted in an interesting paradox; the overwhelming majority of the world's children lived in parts of the world with massive limitations in resources and systems to deliver basic pediatric heart care, yet the available science increasingly focused on niche areas and very specific issues that affect a small minority. While these issues are of some interest to everyone, the available science has not helped us address a very fundamental issue — *how can we deliver comprehensive quality care for the average child with heart disease living in a resource-constrained environment?*

In the 6 years since the inaugural issue, the Journal has received an increasing number of articles from resource-constrained environments. Interestingly enough, a significant proportion of manuscripts are from advanced nations. While the Journal has successfully served as a forum for pediatric cardiac professionals from low and middle-income nations and emerging economies, the specific challenges of delivering pediatric cardiac care in the face of resource constraints could have perhaps received more attention. The majority of original articles in the Journal continue to look at issues that are not unique to the limited-resource environment.

This editorial attempts to systematically introduce the idea that delivering pediatric heart care in the face of resource limitations needs to be approached with an innovative mindset. It is also being written with the hope of setting a stage for a series of manuscripts in forthcoming issues that specifically examine the challenges, suggest solutions and share success stories from resource constrained environments.

DEFINITION

We should perhaps first start by defining “The Limited Resource Environment”. This definition is clearly subjective and quite relative. Professionals in even the most advanced centers are likely to perceive limitations and may have a wish list of resources that they would like to acquire. Resource limitations exist in a wide spectrum. At one end of the spectrum is the situation that affects the poorest regions of the world where there is no pediatric heart care whatsoever. This is true of the most nations in Africa, large parts of Asia, South and Central America. There are no dedicated professionals and no centers with capability of performing pediatric cardiac surgery or catheter interventions. Progressing along this spectrum is the situation where diagnostic facilities are available and perhaps limited facilities to operate and intervene on selected older children with straightforward conditions. Performing infant and newborn open-heart operations requires a quantum leap in resources and expertise. Typically, the need for such centers is felt in regions where infant mortality has reduced to the 20/1000 or lower. They are often limited to larger cities and metros because of a variety of logistic and economic reasons. Establishing such centers is challenging because a number of basic requirements need to be fulfilled (See Table).

Table: Requirements for developing a successful comprehensive pediatric cardiac service

Robust infrastructure
Quality equipment
High level of skill among caregivers
Cohesive teamwork
Supportive administration
Well-developed and mature referral base
Favorable economics and human development in the region
A system for charitable care
Sustainable systems and services: Education and training
Ethical practice environment that is not totally profit driven

Notwithstanding these challenges centers have been successfully established in emerging economies (China, India, Sri Lanka, Pakistan, Bangladesh, Thailand, Vietnam, Malaysia and, Brazil). Selected centers have achieved outcomes comparable to programs in high-income countries and this has been achieved with substantially fewer resources and at a fraction of costs of care.

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ATTRIBUTES AND QUALITIES REQUIRED FOR THE RESOURCE-CONSTRAINED ENVIRONMENT

In my view the key requirement required to overcome the challenge of resource-constrained environment is in the collective acquisition a specific mindset by all members of the team. The mindset is best characterized by a list of attributes that are fundamental to the success of the program and most pediatric cardiac professionals (cardiologists, cardiac surgeons, intensivists and anesthesiologists) who work in resource-constrained environments need to have them. Established training programs in advanced nations often do not prepare the trainee for the specific challenges in these environments. I have prepared a list (below) that may not be complete but hopefully captures the most important requirements:

1. *A deep-rooted desire to reach out to and serve the needs of the average child in the region:* As a first step, it is necessary to know where the typical family lives and do they actually access tertiary hospitals with pediatric heart programs. Economic, logistical and cultural barriers may prevent a significant proportion of patients from reaching the ivory towers of high-tech hospitals. It may be necessary to step into the community through outreach programs and camps to understand the barriers. Conscious and deliberate efforts to explore the socio-economic condition of every family often dramatically change our perspective about addressing their clinical needs. This enables development of thoughtful and contextually appropriate management strategies recognizing the challenges that individual families face.
2. *Willingness to multitask:* In most developing nations and emerging economies the shortfall in human resources are significant. The luxury of having experts with very specific domains of expertise is simply not economically viable. It is therefore imperative that pediatric cardiac professionals acquire a wide range of skills that will enable them to function effectively in varied situations. For example it is quite realistic for a pediatric cardiologist to acquire a high level of skill in imaging (Echocardiography) and invasive work. It is often also possible for the same person to assist in intensive care, interpret common arrhythmias at the bedside. These skills are quite complementary and often improve efficiency.
3. *Willingness and courage to emerge from the traps of our conditioning:* Our training and education is largely conditioned by the published clinical experience and research from established pediatric heart program in the west. While it is true that these programs set very high standards of care and produce exceptional outcomes, the guidelines that they follow and recommend are sometimes not practical in most

resource-constrained environments. We are also often conditioned to equate performing complex procedures (such as the double switch procedure) to “progress”; this capability may not be relevant to the society if we deny care to the average infant with a straightforward lesion (such as a large ventricular septal defect).

4. *Improvise, innovate and invent:* A deep-rooted desire to reach out to every patient is often a strong stimulus to improvise, innovate and invent. A number of innovations have been developed and refined in resource-poor environments in an effort to reduce costs in various facets of pediatric heart care. It is important to systematically document the safety and efficacy and disseminate details through peer-reviewed publications.^[1]
5. *Develop pragmatic case selection strategies; working within limitations of the system:* It is always an ethical challenge to deny care to an individual patient in order to preserve the larger interests of a fragile system. For example, most programs in the developing world do not attempt the Norwood operation. Many programs prioritize straightforward lesions correctable through a single operation over complex multi-staged procedures such as single ventricle palliation.
6. *Willingness to tailor solutions according to the socio-economic condition of the families:* Deviations from “standard” practice are common in the face of economic constraints particularly when families have to pay from out-of pocket. For example: The inability to afford a conduit may necessitate palliation with a bi-directional cavo-pulmonary shunt in an infant or a young child with transposition, ventricular septal defect and pulmonary stenosis.
7. *Reluctance to accept expensive new technology without proof of incremental benefits:* While it is true that technological advances have contributed substantially toward improving the outcomes in the care of children with heart disease, it is also true that very expensive new technology has often found its way into mainstream practice without any form of audit on cost versus incremental benefit. Examples of such high-end technology include, three-dimensional echocardiography, hybrid cath lab-operation theater suites and robotic surgery. The actual numbers of patients where they truly make a difference could be quite small and it may not justify the overhead costs that will have to be shared by all, including the vast majority in whom the technology does not have an application.
8. *Focus on simple quality improvement (QI) measures that make a big difference in outcome:* A number of simple QI measures that can significantly improve outcomes can be introduced at low cost with little resources. Two examples include establishment of

a robust infection control and prevention program in the intensive care unit^[2] and implementation of a surgical safety checklist.^[3,4] A number of mental barriers may have to be initially overcome in order to successfully engage all stakeholders. However, once outcome improvements become apparent, it becomes progressively easy to implement QI systems.

9. *Willingness to educate, train and mentor a variety of health professionals:* Education and training caregivers at all levels is a valuable investment because it empowers them. This is particularly true for nurses. Nurse empowerment directly translates into improvements in outcomes through improved vigil, better infection control and greater motivation through a sense of ownership of the results.
10. *Willingness to systematically document practices, results and share with others through contextually relevant research:* Systematic documentation of various strategies adopted to enable delivery of care at a lower cost without compromise in quality is important. Consistent documentation of these practices in multiple centers enable wider acceptance. As mentioned at the beginning of this editorial, one of the goals of the Annals of Pediatric Cardiology was to serve as a forum for the developing world and emerging economies to share cost-effective practices.
11. *Willingness to explore avenues for funding individual patients:* In the absence of universal health care, coverage through public health insurance, it is important to explore avenues to raise resources to fund individual patients by connecting them with potential donors and philanthropic organizations.
12. *Willingness to make personal sacrifices:* The paucity of trained manpower often translates into a situation where there is a need to work for longer hours without substantial additional economic benefits. Pediatric cardiac professionals in resource-constrained environments invariably have to make considerable personal sacrifices in order to deliver care to a large number of patients.
13. *Develop a trusted relationship with the health administrators:* Many health administrators do not easily understand the fact that pediatric cardiac care is resource intensive, outcomes can sometimes be quite unpredictable with individual patients and the returns on investment may not be comparable with other medical or surgical specialties. It is important to partner with administration and communicate regularly, effectively and consistently about the specific challenges faced while taking care of children with heart disease.
14. *Developing partnerships:* In spite of substantial differences in practice environments, a lot can be learnt from the experience of established programs in high-income nations. Speaking for myself, I can

say that the most valuable lessons I learnt from the Children's Hospital, Boston, was the importance of nurse empowerment, systems and protocols in intensive care, comprehensive and systematic echocardiography for pre-operative evaluation, patient safety protocols in the catheterization laboratory and patient data management. At a more advanced stage, partnership and mentoring need to develop among the programs in the low and middle-income countries, with shared problems and challenges.

SUSTAINING THE EFFORT

The biggest challenge that pediatric heart programs in the developing world face relate to maintaining the standards over extended period of time. Leading programs in the west (e.g. Children's Hospital Boston, Hospital for Sick Kids, Toronto) have sustained exceptional standards of care and maintained leadership positions for several decades by paying very close attention to a number of key issues.

Key short-term requirements include attention to staff retention and long-term requirements include development of robust systems for training successive generations of caregivers. Careful attention to identifying and nurturing leadership in each discipline is also vital to ensure that the vision and goals are maintained over extended periods of time.

I will use an analogy from the world of sport to explain the idea of sustainability. Among the 36 teams that made it to the recent football world cup final there were small countries with substantially fewer resources (Costa Rica and Columbia are good examples). These were able to successfully compete with countries with vastly better resources up until the quarterfinals. However, beyond this stage the player attrition from injuries affected these teams more because of their limited bench strength. The smaller nations were unable to sustain their efforts and eventually accomplished teams with a good bench strength prevailed.

There are specific threats to sustainability in newly established programs in the developing world. Firstly, unlike in high-income countries where nurses have a robust career path and greater professional status (nurses are readily included in professional societies such as the American Heart Association), nurses from programs in low and middle-income countries have vastly inferior salary and professional status. The virtual absence of structured training programs for pediatric cardiac surgeons and pediatric cardiac intensive care is also major sources of concern for the future. One of the goals of professional societies from emerging economies (such as the Pediatric Cardiac Society of India-PCSI, Asia Pacific Pediatric Cardiac Society-APPCS) should be

to systematically deliberate on these challenges and develop systems to address them. The Annals of Pediatric Cardiology can be the forum for the deliberations and publication of blueprints for the future.

*“Ability to work together towards a common vision,
To direct individual accomplishment towards
organizational objectives*

*The fuel that allows common people to obtain uncommon
results”*

Andrew Carnegie

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