

Improving Pediatric Cardiac Surgical Care in Developing Countries: Matching Resources to Needs

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This article reviews a systematic approach to the design and support of pediatric cardiac surgery programs in the developing world with the guidance and strategies of Children's HeartLink, an experienced non-government organization for more than 40 years. An algorithm with criteria for the selection of a partner site is outlined. A comprehensive education strategy from the physician to the allied health care provider is the mainstay for successful program development. In a partner program, the road to successful advancement and change depends on many factors, such as government support, hospital administration support, medical staff leadership, and a committed and motivated faculty with requisite skills, incentives, and resources. In addition to these factors, it is essential that the development effort includes considerations of environment (eg, governmental support, regulatory environment, and social structure) and health system (elements related to affordability, access, and awareness of care) that impact success. Partner programs should be willing to initiate a clinical database with the intent to analyze and critique their results to optimize quality assurance and improve outcomes.

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In humanitarian medicine, there is room for cooperation rather than competition, because the people in need outnumber those able to provide assistance. The goal of improving access to care for the majority of children born with congenital heart disease can only be achieved by building a coalition of the groups involved in structured international projects with a coordination of their efforts.

Epidemiology and Globalization of Care for Congenital Heart Disease

Advances in the diagnosis and treatment of congenital heart disease have resulted in the vast majority of treated children surviving into adulthood. Early mortality associated with surgery for most of congenital cardiac anomalies has been reduced to 5% or less, and emphasis is now focused on decreasing morbidity and improving quality of life. Unfortunately, this progress has, for the most part, been limited to the developed world.

It has been well documented that there is a maldistribution of access to cardiac care, particularly in children, in the "less privileged parts of the world." As we move into the future, it is critical and essential for physicians to be actively involved in political, economic, and social aspects of the society to defend the interests of the impoverished around the world. Although this article focuses on the situation in the emerging countries, "the less privileged parts of the world" can be anywhere, and are not necessarily limited to economic con-

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straints. Lack of diversity because of social, intellectual, educational, and professional inbreeding, the latter representing cultural stagnation, can easily be responsible for the lack of scientific progress and development.¹

The incidence of congenital heart disease is approximately 1% of live births, thereby making it the most common major congenital abnormality. Every year, approximately 90% of more than 1,000,000 children who are born with congenital heart disease around the world receive suboptimal care or have no access to care.^{1,2} In addition, those affected by non-congenital pediatric heart conditions also require and deserve prevention, diagnosis, and treatment. Consequently, there is a critical need to establish and enhance an increased number of reputable pediatric cardiovascular programs in developing countries. The recommended strategy is based on a long-term educational and technical support model so that as case volumes increase, quality improves, and mortality and morbidity decrease.³⁻⁵ Humanitarian outreach activities and medical/surgical volunteer efforts should focus in this area and surgical tourism should be avoided. Strategies have included matching a potential partner site in the developing world with a seasoned, reputable pediatric cardiac supporting team from elsewhere in the world (ie, the creation of “twinning programs”). Twinning is the pairing of two cardiac programs (one an established center of excellence, and the other an evolving program in the developing world) to establish a relationship of value to both organizations. In those countries where maldistribution of access is the main problem, the existing centers of excellence can contribute to the creation and support of new centers—“national twinning programs”—an alternative model to be explored.

The objective of this review is to examine the specifics of a successful medical non-government organization’s (NGO) approach to a long-term education and support model (“twinning program”), a partner site selection process, and approaches to program development. Children’s HeartLink (CHL), based in Minneapolis, MN, is an experienced medical NGO with a 40-year history of promoting sustainable programs to prevent, diagnose, and treat heart disease among children in underserved regions of the world. Policies and strategies that have been successful with CHL will be reviewed.

The goal of improving access to cardiac care for the majority of children born with congenital heart disease cannot be achieved through the efforts of medical NGOs working in isolation. Ideas to improve effectiveness and efficiency around the world by building a coalition are explored. The newly established World Society for Pediatric and Congenital Heart Surgery can serve as a facilitator in the building of this coalition “Working Together” with medical NGOs such as the CHL.

Establishing Partnerships to Improve Cardiac Care

Partnership

The fundamental reason for forming a partnership is the goal of both organizations to help children with heart disease.

CHL views a partnership as an ongoing relationship where partners depend on each other for something of value. Importantly, such a relationship evolves over time. It has been the experience of CHL, that in forming partnerships, the “twinning” concept appears to be the most productive. For this reason, CHL is moving in this direction with all of its partner sites. Ultimately, such twinning relationships become more collaborative (usually 4 to 5 years), where both organizations are more equally supporting each other in providing cardiac services to needy children and assisting other cardiac programs in the area.

Resources Available

CHL is fortunate to have access to a wide variety of excellent health care providers from reputable institutions, equipment and supply manufacturers, and general community support for humanitarian efforts both on a local and international basis. As a private charitable medical NGO, CHL is dependent on the philanthropy and generosity of many individuals, corporations, and foundations for the funding and donation of other resources that make this type of work possible.

Requirements for Successful Partnership

In establishing partnerships in more than 10 countries, CHL has learned that the following factors are essential for a potential partnership to be successful:

- 1) A commitment to work together in a spirit of collaboration, which implies a sharing of responsibility, open exchange of information, and commitment of resources, for the enhancement and expansion of cardiac services for children.
- 2) A commitment to track and measure results of their cardiac services and efforts to enhance the program (ie, increase volume, improve quality, and reduce mortality and morbidity). This begins with implementation and use of a database with periodic review of outcome results by the institution.
- 3) A commitment to establish/designate an acceptable structure (such as an NGO or local foundation) through which CHL’s resources can be contributed and distributed for children assisted.
- 4) A commitment to build local government and community support for future program sustainability with long-term goals and objectives established (5- to 10-year view).

Basic Requirements for a Pediatric Cardiac Surgery Program

- Institutional Support: Needless to say, institutional support means the active participation of those at the top in addressing and resolving other limiting factors that can eventually narrow down the number of the binding constraints, creating a mutual benefit of changing for the better in a partnership with synergy.

Patient-Centered Care

Multidisciplinary, integrated approach

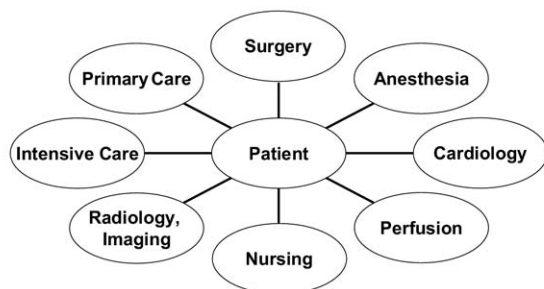


Figure 1 A patient-centered multidisciplinary, integrated team approach to the cardiac care of children.

- Integrated Approach (Fig. 1): Team work, in which all members of the cardiovascular services (a cluster of people with similar interests and focused on excellence) contribute, although in different degrees, to the quality of the final outcome; in another words, willingness to face reality and agree to do adaptive work throughout the organization.
- Volume-minimum of approximately 100 surgical cases per year, with the potential to increase to 300 to 500 cases per year or more over an approximate 5-year period.
- Diagnosis: Pediatric cardiologists and related specialties.
- Treatment:
 - 1) Congenital cardiac surgery
 - 2) Congenital cardiac anesthesia
 - 3) Nursing
 - 4) Interventional cardiology
 - 5) Other allied health (eg, perfusion, social work, pharmacy, blood bank services etc)
- Pediatric Intensive Care: Preoperative evaluation and optimization of patient condition; postoperative care.
- Follow-up and application of methods for meaningful comparisons of in-hospital mortality for groups of children undergoing surgery for congenital heart disease, such as the Risk Adjustment for Congenital Heart Surgery (RACHS-1) methodology or the Aristotle Basic Complexity Score (ABC Score) and Aristotle Basic Complexity Levels (ABC Levels).
- Utilization of the clinical material for contributions to professional societies, national and international journals.

In institutions with rigid structures, all of their tenured staff should participate, compromising and agreeing to work toward these basic requirements, using the method of criticism-self criticism and rectification to address not only technical issues but also dysfunctional behaviors.

Partner Site Selection Criteria

An existing, active (performing approximately 100 cardiac procedures per year) cardiac program is preferred. Required active personnel at the partner site should include pediatric cardiac surgery, pediatric cardiology (echocardiography, cardiac catheterization), anesthesiology, perfusion, intensive care, primary care, and nursing (Fig. 1). Other allied health care providers, such as pharmacists, respiratory therapists, social workers, biomedical engineers, blood bank technicians, and interpreters, are also important. Ideally, the preferred supporting medical center would be:

- 1) A tertiary care center that is affiliated with a university and provides education and training to medical personnel.
- 2) A recognized center of excellence.
- 3) A willingness to commit to the “twinning” concept:
 - a) Belief that the relationship will produce mutual benefits for both partners (ie, staff learning and satisfaction, and treatment of patients).
 - b) Reasonable availability to work with the twinning site by providing complete teams and individuals to go to the site; access to team members (by phone or e-mail) for site team members throughout the year for consultations, advice, and guidance.
 - c) Willingness to work with the resources available at a site.
 - d) Willingness to learn about the local culture.
- 4) Support from a team’s institution.
- 5) A willingness to commit to a multiple-year relationship.

The partner site program should have:

- 1) A commitment to track and measure program outcomes (eg, begin a database).
- 2) A children’s hospital or a hospital with an established pediatric and neonatal intensive care unit.
- 3) Evidence of local and provincial government support.
- 4) A commitment to advancing their program (both qualitative and quantitative) with written objectives and support from the hospital administration and long-term goals.
- 5) The potential to become a regional or a national cardiac center of excellence – because of need in the region (ie, high volume institution), size of facilities, and lack of another existing regional center.
- 6) A commitment to providing pediatric cardiac services to poor and financially needy patients.

Part of the selection process is also a gut feeling for a potential site’s responsiveness (ie, openness and willingness to share responsibilities for advancing their program [volume and quality]) and to work with CHL involvement (Fig. 2). The identification of this “chemistry” factor in the relationship with a potential partner program is an essential step in the process. The goal is to identify a program (“fertile site”) that has the potential to become a medium/high volume, high-quality institution (* in Fig. 2) and avoid programs that may have too many constraints that would limit or prohibit

The Evolution of a Program

Volume Outcome Relationship

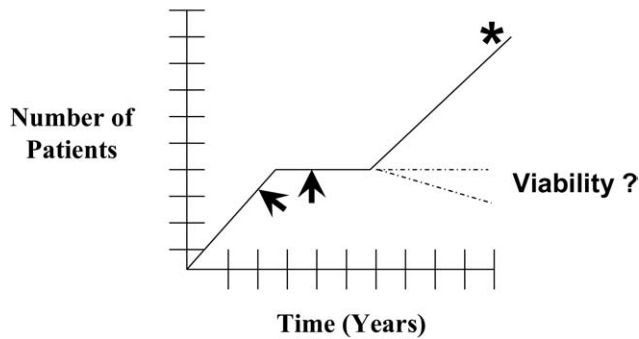


Figure 2 Hypothetical volume-outcome relationship in the evolution of a cardiac surgery program. As the number of patients undergoing surgery increases, the quality (ie, improved outcome) increases. Arrows represent the level that a program is at when the partnership is initiated. The asterisk indicates the expected level that the program should be at in approximately 5 years. It is important to avoid twinning with programs that have limitations (hospital governmental, social, etc.) that preclude successful growth (dotted lines).

their development and viability (dotted lines in Fig. 2). Consistent, strong medical leadership within the institution is essential for this to be successful.

Partner sites can range from emerging centers requiring large amounts of assistance, to the advanced center that only needs very specialized, targeted assistance for specific complex procedures or techniques. Although focusing primarily on emerging centers, CHL considers partnerships with these more advanced centers to meet one or more of the following objectives:

- 1) A program that can serve as an in-country training site (training the trainer approach) for other evolving programs in the country that CHL is working with.
- 2) The site offers an opportunity to assist large numbers of needy children.
- 3) The site provides important political/community leadership support for CHL efforts in other parts of the country or region.

Partnership Development Phases

Once a particular underserved country or region is identified through requests for assistance or recommendations, the following phases of involvement are carried out (Fig. 3):

First Phase

Research into a potential program is initiated because of one or more of the following:

- 1) Request from an existing international cardiac program for assistance.

- 2) Suggestion from the CHL network (ie, medical volunteer or one of their contacts).
- 3) A strategic decision by CHL to focus on a particular country or region because of opportunities for alliances with other organizations or funding sources.

CHL becomes informed about the cardiac program(s) in the area, health conditions and infrastructure in the country, and the demand for services. CHL staff explores Internet sources, printed materials, individual contacts that have knowledge of the site(s), and areas being considered. Attention is given to sites that meet the criteria outlined above. In addition, the cardiac program must be valued and supported by hospital administration and local government officials. The site should also be willing and able to assume some responsibilities (financial/coordinating) for CHL's on-site involvement with the twinning program. This phase also involves review by CHL's development staff on potential sources of financial support for a partnership in the country being considered.

Second Phase

On-site evaluation of the potential program with a small team consisting of one or two medical volunteers and a CHL staff member to meet with key hospital and community representatives to discuss and observe in more detail the site's resources, needs, and priorities.

Third Phase: Pilot Program/Site Assessment

After site selection, CHL identifies an experienced cardiac team (ie, the supporting twinning program), which is usually a University-based or academic program already involved with training and education. This program can be from anywhere else in the world. During the first visit, the twinning program conducts a more comprehensive assessment of the site's resources, scope, and range of services, and determines the areas for improvement. This usually involves a complete cardiac team (seven to eight medical volunteers – surgeon, cardiologist, anesthesiologist, intensivist, perfusionist, nurses, biomedical engineer, interpreters, etc.) who can provide a full assessment of the program from each team mem-

Figure 3 The CHL partner site relationship cycle (see text for details).

Pediatric Patient Volume

1st Hospital of Lanzhou University

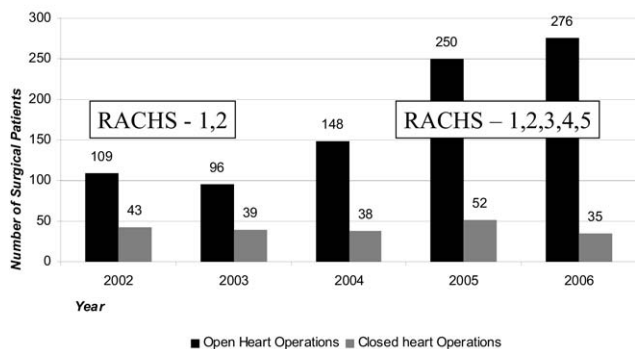


Figure 4 Pediatric cardiac surgical patient volume at the First Hospital of Lanzhou University. The number of open and closed cases steadily increased over a 5-year period. In addition, the complexity of cases increased over the same time frame (ie, there was a greater number of RACHS-1 categories 3,4, and 5 cases in the latter years).

ber's perspective. At the end of this visit (approximately 1-week duration), the supporting team, the site team, and a group of selected hospital administrators/officials meet to discuss their needs and priorities. A plan for the subsequent year is then developed to start addressing these needs during this "pilot" program stage. At this stage, it is also important for the partner site to articulate its own vision of needs and plan for the future of their program.

Fourth Phase: Active Partner Site

Assuming the relationship goes well the first year, this stage endures for the next 3 to 5 years when CHL works in collaboration with the site to provide a variety of assistance (both on and off site) depending on the needs and priorities of the partner site and resources available. The "twinning program" is established and is paired with the partner site for this collaborative, educational experience (1 to 2 visits per year) to help facilitate program development. Additional support may include:

1) Education and Training. Provides educational opportunities for cardiac team members (eg, attending and resident physician staff, nurses, etc.), both on-site (annual or biannual medical team missions with the twinning program) and off-site training. In addition, periodic visit(s) by requested consultants for evaluation/recommendation of specific areas (eg, infection control) occurs in between team visits. Also, *in between team visits* there is availability of twinning team members to respond to ongoing questions and proposals. These team visits create learning on both sides of the table, with impacts on the visiting team that include a widened world view and exposure to the resourcefulness and strength exhibited in the ability of the partner site to adapt and serve patients despite limited resources. Off-site training can range from short (1 to 5 days) to multiple month observation experiences, to matriculation into certified training programs

for 1 to 2 years (eg, pediatric cardiac surgery fellowship, etc.). These opportunities can be arranged at another established/certified site within the same country, or elsewhere in the world. This long-term education strategy is the mainstay of program development.⁶ This helps facilitate the partner site to develop a comprehensive patient-centered, quality care approach (Fig. 1).

Outcomes of a program in central China that had a successful partnership with CHL are depicted in Figs. 4 and 5. In addition, at this site, the number of competent and dedicated medical staff was refined, educational opportunities were provided to many medical team members (physicians, surgeons, nurses, etc.), the number of cardiac surgery cases increased, and the early mortality and morbidity decreased in spite of an increasing number of progressively more difficult cases (ie, RACHS-1 categories 3, 4, and 5). This educational format with improvement in outcome has also been documented elsewhere.⁷

Twinning programs can also coordinate web-based educational opportunities, including web-based joint conferences and web-based consultations about complex patients.

2) Funding Support for Treatment. Funding provides, on an annual basis, partial funding for a negotiated number of surgical cases.

3) Technical Assistance. Technical assistance provides consultation by experienced and knowledgeable health professional volunteers on various aspects of cardiovascular services. This may range from prevention to treatment, nursing management, the assessment and improvement in infection control programs, blood bank management, telemedicine conferences and consultations, medical equipment repair and maintenance (biomedical engineering), funding and implementation of rheumatic fever prevention programs, and long-term program planning.

1st Hospital of Lanzhou University

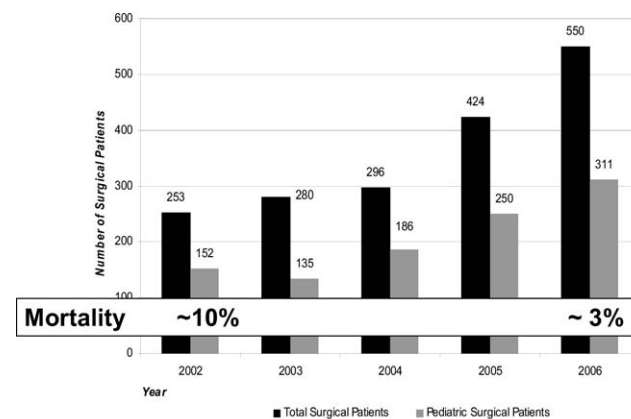


Figure 5 Cardiac surgical patient volume at the First Hospital of Lanzhou University over a 5-year period. Early mortality decreased from approximately 10% to 3%, while there were an increased number of more complex cases (ie, RACHS-1 categories 3, 4, and 5) in the latter years.

4) Database and Quality Assurance. The importance of initiating a database and implementing a quality assurance program is essential. Measurable progress motivates all components of the partnership. The limited version of the Society of Thoracic Surgeons (STS) database with classification of cases by degree of difficulty (eg, RACHS-1 categories; Fig. 4) and outcome (Fig. 5) is strongly encouraged and implemented.⁸⁻¹⁰

5) Critical Supplies and Equipment. Provides certain essential supplies depending on the site's need and efforts to keep patient costs to a minimum (eg, prosthetic heart valves, cardiac grafts/patches, specialty catheters for interventional procedures, bypass pump disposables, or medications for the operating room, cath lab and/or postoperative care) limited to team visits and requests for a specific patient. Occasionally, CHL also assists with the acquisition of medical equipment (eg, ventilator, hemodynamic monitors, etc.) by means of donation or facilitated purchase at a substantially reduced price. It is a fact that with the equipment that is discarded every year from hospitals of the more privileged countries (eg, cardiopulmonary bypass machines, monitors, infusion pumps, ventilators, etc.), it is possible to equip a very good unit. Unfortunately, in some countries the donation of good used equipment and supplies is no longer possible. Although donation of equipment and supplies is important, it is also crucial to assure that efforts should focus on working with the indigenous resources that are already available at a given site.

6) Prevention and Early Screening Programs. Recognizing the reality of these programs being overwhelmed with treatment efforts, it is also important and essential to pursue screening programs for earlier detection of congenital heart defects, and to apply more widespread prevention programs. A crucial component of site assessment is developing a plan for the screening of children with potential congenital heart disease. Programs in the early stages may operate on only 10% to 15% of children born with congenital heart disease, and only those who have already been through a process of "natural neonatal selection." It is important for cardiologists to initially improve screening by creating simple peripheral outreach clinics (if at all possible within the parameters of the existing public health system), leaving the development of expensive programs for interventional cardiology (ie, device closure for patent arterial ducts and atrial septal defects) for a later stage.

Fifth Phase

Once a site reaches a level of consistent services (with improved outcomes) appropriate to its resources and the demand for services, the relationship enters the phase of "ongoing collaboration." With a common mission of assisting children with heart disease and helping other programs in the region, there is value in collaborating with such sites to maximize the possible impact on the cardiac needs of the region.

End Phase

When there is a lack of shared objectives or unfavorable/unworkable circumstances, support is withdrawn and the partnership is ended. Examples that can result in withdrawal of support include lack of hospital priorities for further development of pediatric cardiac services, lack of medical leadership with a coordinated team of focused individuals, or other factors such as political instability or security issues.

Program Development

The road to successful development and change in a partner program depends on numerous variables that include government support, hospital administration support, consistent medical staff leadership, and a medical staff that is—receptive—committed to protocolizing perioperative diagnosis/management algorithms, data acquisition, and implementation of a quality assurance program.¹¹

In principal, all of the above seems obvious; however, the ability to create successful change and develop action plans in the developing world is hampered by a variety of factors. Complex change requires vision, skills, incentives, resources, and an action plan to avoid confusion, anxiety, gradual change, frustration, and false starts. The approach and management of change can be summarized in Fig. 6. When goals and objectives have been achieved, and successful change has occurred, it is important for the institution to recognize, celebrate, and if possible to reward these accomplishments.

Economists, researchers, government officials, and policymakers look for interrelated factors that inhibit growth. Binding constraints can limit program growth. Constraints, bottlenecks that restrict an entity, project, or system from achieving its potential, are considered "binding," if changing them also changes the optimal solution. They can be identified using a growth diagnostic tree that includes potential limitations (Fig. 7). When evaluating this diagnostic ap-

Managing Complex Change: Diagnostic Approach

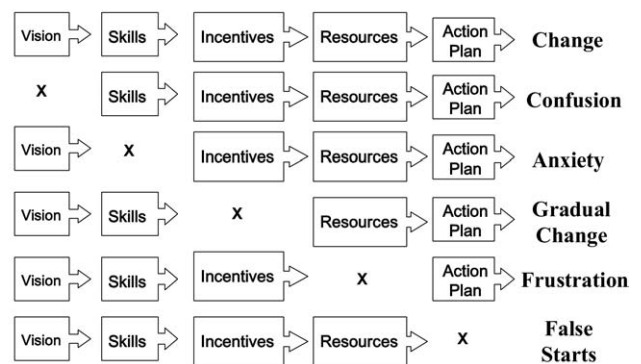


Figure 6 Diagnostic approach to the management of complex change. Successful change occurs when there is a vision, appropriate skill sets, incentives, resources, and an action plan. (Data from Ambrose D. 1987; *Managing Complex Change*. Pittsburgh: The Enterprise Grp Ltd.)

The Quest for Growth: Diagnostic Approach

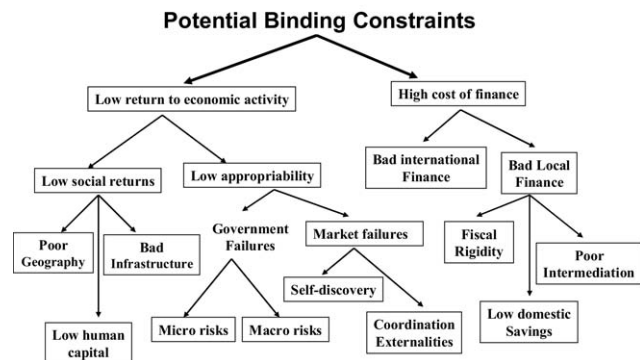


Figure 7 Diagnostic tree used by economists to identify from a list of interrelated factors, which are the most binding constraints that can affect the quest and success of growth. A similar approach, with different factors, can be used in program evaluations and developments.

proach during the growth period, a few points should be considered:

- There are many constraints to growth, but not all are binding - Growth diagnostics seeks to identify a causal relationship between public policy and growth. Treating the symptoms will not cure the illness.
- Binding constraints change - They change for two reasons: (1) in the normal course of successful development, binding constraints are removed and the program will grow until a new binding constraint limits it, and (2) even when no binding constraint is removed, events can occur so that new binding constraints will supersede earlier binding constraints.
- Some factors that limit growth should be seen as parameters, not constraints. Some constraints are imposed by man and can be eliminated by public policy, but others are imposed by nature or by history, and public policy can only ameliorate their impact.
- It is difficult to prove that a constraint is binding. Given a list of constraints, the search for the binding constraint involves qualitative investigation. When a hypothesis is tested against multiple implications and is not rejected by any of them, we then gain a degree of confidence that we have identified the binding constraint.¹²

In attempting to encourage successful program development at a “twinning site,” it is essential to consider the larger picture of what makes a particular medical program successful. The foundation of the success in any program development effort is in understanding the environmental and health care system factors along with the medical factors involved in the development. *Environmental* factors include governmental support for the health system, cultural attitudes toward medical treatment (and western medicine in particular), and regulatory policies on the use of supplies and devices that are almost impossible to change. An example of this is the Chinese government’s current ban on importing used medical equipment for use in state-sponsored hospitals. While it is

assumed that there are legitimate reasons for this policy, this type of restriction does hinder overall progress because it slows departmental capacity and growth, limiting surgical volume. The lack of internal funds to purchase new equipment for the partner site results in a standstill in program growth. Government policies that would allow acquisition of good (ie, working condition and serviceable) used or donated medical devices that can be properly serviced at a partner site would facilitate efficient program growth. This is just one example of a limitation that ultimately influences the rate of program growth and development.

The health care system factors that have the most impact to deliver quality health care are *affordability* (financial element), *access* (logistics element), and *awareness* (knowledge element).¹³ These factors are more easily influenced than the environmental factors, and once they are understood can be used to magnify the results of a program’s development or a development effort. They are essential to the health care supply chain, which is a term used to describe the flow of goods and services from where they are developed to where they are ultimately delivered to patients. For a successful health care supply chain there must be three critical elements of considered in developing the relationships between organizations.

The financial element or the *affordability* construct is characterized by the ability of patients to pay for the necessary treatment of adverse health conditions and the parallel ability of the health care provider to offer the necessary services. The logistics element or the *access* construct is centered on the existence of the necessary infrastructure required for diagnoses and care delivery, including facilities, equipment, and supplies. The final construct represents the knowledge element and is titled *awareness*, which encompasses the patient’s knowledge of available health services and disease conditions as well as the physicians’ and allied health workers’ skills at diagnostics and treatment to provide the required care. Awareness and education are closely related. “THE COMMONWEALTH REQUIRES THE EDUCATION OF THE PEOPLE AS THE SAFEGUARD OF ORDER AND LIBERTY”—inscription at the Boston Public Library—reflecting the importance of education in society. The dynamics of how these constructs are interrelated and influence system outcomes for a specific program development effort are shown in Fig. 8.

While all of the ways in which these health system constructs are related has not specifically been determined, a study of the dynamics of the system illustrated in Fig. 8 shows the weight of these health system factors on the medical factors influencing patient treatment listed in the diagram as “Care Delivery.” The diagram is designed to illustrate the importance of each of these elements and to propose a framework that increases our understanding of how to achieve quality health care in high volumes for underserved populations. The purpose of this framework is to give guidance for health care providers to focus their improvement and innovation initiatives on specific aspects of their administration and larger supply chain initiatives toward the identified factors (diagnostic approach) that influence the elements of finance, logistics, and knowledge in the health care system. It

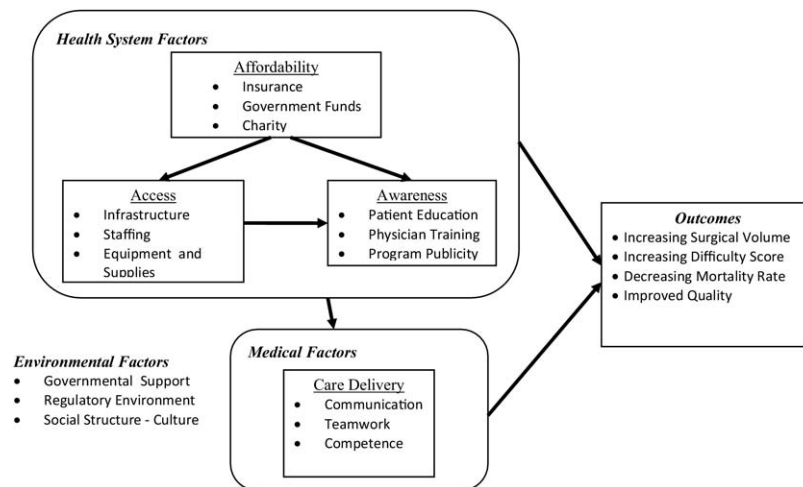


Figure 8 Relationships between the constructs of awareness, access, and affordability, and their influence on medical factors and system outcomes. As shown, these relationships are subsumed by the influence of other environmental factors, generally outside the control of the organizations composing the health care supply chain.

has been shown that these efforts will significantly impact their ability to serve those in need of medical care in underserved communities. The most revealing of the influences of these system dynamics are the impacts of *affordability*, *access* and *awareness* on the “Care Delivery” construct itself. These may have initially been considered as independent of one another, but an increasing amount of evidence both in the business literature and the medical literature shows the importance of business and hospital administrative factors on the treatment effectiveness of the physician and allied health staff. In the end, it is both these system factors and the medical factors that influence the outcomes that are desired for a successful development effort in a partner site. Success in this model is defined in terms of patient volume, case complexity, and decreasing morbidity and mortality.

Building a Global Coalition to Improve Congenital Cardiac Care

The goal of improving cardiac care for all children born with congenital heart disease around the world is a monumental challenge. However, this goal cannot be achieved through the efforts of medical NGOs working in isolation. The experience of CHL and the guidelines presented in this paper should form a solid basis for the appropriate engagement and use of limited resources. Others are encouraged to learn from this experience and tailor their efforts appropriately. Establishing links with other medical NGOs, exchanging ideas and coming to a general consensus that would be desirable for a better utilization of the available resources.

But how do we effect the change in the world architecture sorely needed to achieve this goal on a larger scale? This effort requires the building of a global coalition, working together and not in isolation. Unnecessary competition and duplication of efforts is inefficient and counterproductive, and in the end may not achieve the sustainable results that are essential. The newly established World Society for Pediatric and Con-

genital Heart Surgery (WSPCHS) can and should serve as a facilitator in the building of this coalition, “Working Together” involving medical NGOs such as CHL, following the comprehensive guidelines reviewed in this article. As the largest organization in the world of pediatric and congenital heart surgeons, the WSPCHS could have the potential to mobilize its members for this task. Furthermore, it could assimilate and channel various ideas from its worldwide membership, establishing and recommending appropriate rules of engagement for humanitarian outreach activities. Additional partnerships with professional organizations of related specialties are also needed in this process. To achieve that goal, the WSPCHS is playing a leadership role in the development of the Multisocietal Global Organization for Pediatric and Congenital Heart Disease, which was established during the World Summit on Pediatric and Congenital Heart Surgery Services, Education and Cardiac Care in Children and Adults with Congenital Heart Disease in Montreal, 2008.

Summary

The past 40 years of work by the CHL organization has allowed us to identify some of the key factors relevant to increasing the volume and quality of care offered around the world by pediatric cardiac surgery programs. Congenital heart disease is a global problem and, although diagnosis and treatment for these conditions is now available in some parts of the world, the majority of children suffering from these conditions do not receive adequate (if any) care. We have identified the implementation of “twinning programs” as a successful tool for increasing the availability of care of congenital heart disease in developing countries. The basic selection criteria for choosing a health care organization that is capable of a successful twinning program have been discussed, along with the essential phases involved in bringing one of these twinned programs to an effective treatment level.

Finally, the other factors that influence the level of development that can be accomplished in a particular partner program are discussed and a framework of how these factors influence outcomes in an organization was presented. While this is not a complete solution to the problem of inadequate health care in many parts of the world, we believe it is a significant step in showing how to increase and facilitate the availability of quality health care for children with congenital heart disease around the world.

The concept of “twinning programs” creates a true partnership in these initiatives. Several principles of “twinning programs” deserve re-emphasis:

- 1) When a surgical program in the “developed world” focuses efforts on a single partnership with a surgical program in the “developing world,” the likelihood of sustainability is greater than if a surgical program in the developed world focuses efforts on multiple partnerships within the developing world. However, several programs from the developed world can collaborate to help a single program in the developing world; the key is the coordination of these efforts.
- 2) Improving cardiac surgical services in a hospital can lead to important parallel upgrades in many other parts of the hospital as well.
- 3) Collaboration with medical NGOs and governmental agencies is vital to the success of these efforts. The harmonization of the efforts of multiple NGOs may be the key to the coordination of these efforts on both a local scale and a global scale.

The goals of these efforts of “twinning programs” are multifactorial:

- 1) To help patients in need.
- 2) To educate local health care providers.
- 3) To benefit from a bidirectional exchange of knowledge between both teams that compose the “twinning programs.”
- 4) To help support the programmatic infrastructure of the “developing program” (eg, donation of disposable and non-disposable equipment, maintenance of this equipment, etc).
- 5) To create sustainable programs in developing countries.
- 6) Building community support, awareness, and knowledge.

Collaboration, based on synergy rather than competition, among CHL, other medical NGOs, the World Society for

Pediatric and Congenital Heart Surgery, and other professional organizations can go a long way toward building the necessary coalition to truly provide and improve cardiac care for *the majority* of children and adults with congenital heart disease worldwide.

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