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Review Article

Challenges in setting up congenital heart disease programs in resource poor countries: lack of resources is not the only impediment

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ABSTRACT

Congenital heart disease (CHD) is emerging as an important cause of mortality from noncommunicable diseases in resource poor countries (RPCs). CHD is a resource intensive specialty; therefore, the expensive western model of care is unsustainable in poor countries. Stakeholders in RPCs must constantly innovate to build programs within their own resources to achieve good results. Centers of excellence in developed countries have achieved consistently good results by putting huge emphasis on creating a "culture of safety" around their patients. This is important because whenever safety culture is sidelined or ignored even in these high technology and resource intensive centers, the results are poor and in some instances catastrophic. RPCs do not have fiscal resources to match the technologically advanced programs of the developed nations nor can they afford high maintenance manpower investments. This review suggests that building a "culture of safety" within a CHD service is not dependent on fiscal resources but on the commitment within its leadership to build it.

1. Introduction

Congenital heart disease (CHD) is the most common birth defect with an incidence of about 8 per 1000 live births.[1] It is the leading cause of birth defect–associated infant mortality and morbidity. CHD accounts for about 30–40% of all major congenital anomalies[2] and is one of the most common noncommunicable diseases. Decline in infant and children mortality from communicable diseases has allowed CHD to emerge as the 5th common cause of neonatal mortality by 2030.

Globally more than one million children are born with CHD every year.[3] Excellent outcomes for babies with CHD is the one of the big achievements of modern medicine. A deep understanding of the disease process and supportive technology has enabled surgeons and cardiologists to cure or palliate almost all known forms of CHD. Multidisciplinary teams of surgeons, cardiologists, anesthetists, intensivists, nurses, and perfusionists treat extreme forms of CHD like the hypoplastic left heart syndrome and achieve excellent outcomes. However, this kind of advanced comprehensive care for CHD is only available to about 10% of children living in the developed world.

More than 90% of children with CHD are born in resource poor countries (RPCs).[4] While North America has one pediatric cardiac surgeon per 3.5 million people, in South America one pediatric cardiac surgeon serves a population of 6.5 million and worse still this number goes up to 1 surgeon per 25 million in Asia and about one per 38 million in Africa.[5] Consequently, access to congenital heart surgery (CHS) in RPCs is very limited which accounts for a much higher mortality and morbidity in children with CHD living in these countries. Those who survive without treatment are riddled with complications such as infections, malnutrition, pulmonary hypertension, and heart failure which makes their management very challenging and their outcomes less than desirable.

2. The challenge

CHD is a resource intensive subspecialty. An expensive and sophisticated infrastructure run by highly trained and subspecialized professionals is the hallmark of CHD programs in the developed world. Unfortunately, governments of developing nations do not give healthcare its due priority leaving most of the burden of healthcare expenditure on their citizens. Poor investment into healthcare also translates into less trained professionals in these countries who migrate to the west for advanced training and better reimbursement. Even in affluent settings of the developed world,

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relative resource constraints and lack of trained manpower in the specialty of CHD is not uncommon. Manpower deficiencies in the west are usually filled by fellowship positions that are competitively filled by relatively experienced surgeons, anesthetists, cardiologists, and intensivists from the developing world. This creates a brain drain on RPCs which they can ill afford.

In the light of these challenges, setting up a successful CHD program in RPCs needs constant and innovative thinking by surgeons, cardiologists, anesthetists, intensivists, and other allied professionals who take care of these very sick group of patients. It needs a level of commitment that borders on missionary zeal.

3. Same goal but a different model of care

Success in infant and neonatal cardiac surgery has been enabled by a dynamic shift in the way care is delivered to babies with CHD. The old linear model of pediatric cardiac care in which a cardiologist diagnosed and the surgeon operated and provided postoperative care and follow-up is obsolete. In this model, there was limited interaction between the cardiologists and surgeons that lead to wide gaps in management. Preoperative, intraoperative, and postoperative problems were not managed through a coordinated effort. Owing to poor communication and organization of work between cardiologists and surgeons, valuable information and time was lost resulting in poorer outcomes. Neonatal surgery especially bore the brunt of poorly organized care translating into suboptimal results and a mindset toward palliation.

The new model of pediatric cardiac care that has evolved in western countries has huge emphasis on subsubspecialized care. A modern day pediatric cardiac program in the west is run by 3 distinct teams. A team of cardiologists consisting of interventional cardiologists, noninvasive imaging experts specializing in echo and MRI, and electrophysiologists who workup and diagnose the patient preoperatively. In the operating room, surgeons with the help of anesthesiologists perfusionists and cardiologists specializing in echo carry out operative treatment. Assessment of surgical repair by postoperative echocardiography in the operating theatre performed by a cardiologist is an important component of modern era care. In the intensive care unit, the patient is managed by intensivists who are usually cardiologists specially trained in postoperative management and who can also perform bedside echocardiograms. Surgeons, interventionalists, electrophysiologists, and noninvasive cardiologists are close at hand to augment care in the intensive care unit. Individual members look after specific issues within their domain of care. Subspecialty consults for extra cardiac issues are readily accessible.

Western model of pediatric cardiac care is very expensive and is therefore unsustainable in RPCs. While the need to provide safe care to these very sick babies cannot be overemphasized, stakeholders in RPCs must constantly innovate and build a program around their specific needs, resources, and capabilities.

4. Way to go

Suggestions and guidelines to establish safe pediatric cardiac care in a RPCs have been extensively discussed by experts and are widely reported in literature.[6–12] Experts especially those who practice in RPCs provide a deep insight into the problems encountered in setting up CHD programs in these countries and suggest measures to overcome them. It has been suggested that emulating successful programs within RPCs is a more practical approach for budding programs in these countries because they provide solutions to specific problems encountered in their settings.[13] Following is a briefly summarized review which applies to all resource poor settings:

4.1. Assemble a cohesive congenital heart disease team

4.1.1. Skills and qualifications

Technical skills, nontechnical skills of the CHD team are of utmost importance. Cardiac surgeon, cardiologist, and anesthetist/intensivist should not only have the required competence in their areas of work but also have the skills and willingness to multitask and make personal sacrifices in matters of time and money. A surgeon may set the tone of a program. By keeping ego out of the way and leading with vision, persistence, self-criticism, and patience, a surgeon can oversee the cogs that make up the wheel of a congenital heart program.[14] It is also important that a surgeon knows the limitations of his program and not undertake operations that the program cannot handle.

4.1.2. The collaborators

Critical to the success of any pediatric cardiac program is the relationship between a surgeon and a cardiologist. This is a unique and symbiotic relationship which requires mutual respect and a deep understanding of each other's area of work. Each should know the strengths and weaknesses of the other. A cardiologist routinely evaluates a surgeon's repair by looking at postoperative transesophageal echocardiograms and may evaluate and treat a residual lesion in the cardiac catherization lab if detected later in the postoperative period. A surgeon in turn provides back up if an interventional procedure goes wrong or helps with surgical cut downs if percutaneous access is difficult.

4.1.3. The great multitaskers

Blended cardiologists are subspecialists in one area and take on other areas of care under their wing.[14] They perform echocardiograms, cardiac catherization's, and diagnose and treat postoperative arrythmias when necessary. Anesthesiologists are a vital component of this team. Together with surgeons and cardiologists, they are the great multitaskers who double as intensivists. Anesthetists can perform intraoperative transesophageal echocardiograms and bedside echocardiograms in the intensive care. Junior surgical staff augment the postoperative on-call intensive care team in addition to providing surgical cover for any postoperative complications. Role of nurses cannot be overemphasized. On top of providing routine nursing care, they multitask as physiotherapists, dialysis nurses, and infection control advocates.

4.1.4. Teamwork

The CHS team should strongly believe in collective decision making which should be reflected in multidisciplinary meetings for diagnosis and planning of treatment. Regular quality assurance meetings to improve outcomes and sustained emphasis on cost containment without putting patient safety at risk should be a part of culture of the team. The team should have strong awareness that in CHD management of patients is complex and tightly coupled and even small failures in protocols or processes can lead to poor outcomes.

4.2. Focus on intensive care

A dedicated team specialized in pediatric intensive care leads to better outcomes. Teams that understand the nuances of pathophysiology of CHD are essential for optimal outcomes. A multitasking team of anesthetists, cardiologists' surgeons, and nurses covers diverse areas of postoperative management. Protocol driven care should be preferred. It has been shown that by virtue of standardization of care alone, better results are obtained compared with those achieved by random application of several individually equivalent approaches.[15] Resilience to accommodate alternative

scenarios should be part of a good protocol.

Leadership in the intensive care is very important.[14] An intensivist should ideally take charge as the pediatric intensive care unit (PICU) leader because of the ability to oversee many areas at the same time. An intensivist knows what's going on in the intensive care, in the operating room, in the cardiac catherization laboratory and can keep tabs on any new admission who may need urgent intervention. Surgeons are mostly preoccupied with performing surgery and managing the extremely complex environment of the operating room. It would be unreasonable to expect them to provide leadership of the intensive care. A PICU leader coordinates the work of the multidisciplinary team, fosters teamwork, provides support, and supervision to junior staff, mentors budding intensivists, and ensures quality.

4.3. Establish a referral base

A referral base is vital to sustain a CHD program. Cardiologist equipped with an echocardiography machine and a pulse oximeter at local maternity hospitals will ensure a steady supply of neonates with CHD. It is an absolute necessity to have prostaglandin infusion available in these hospitals at all times. If possible, satellite clinics for pediatric cardiologists in community hospitals at regular intervals can help capture infants and children who were not diagnosed in neonatal period and are able to survive their disease. A significant number of adults with undiagnosed CHD can also be captured through these clinics. Community clinics can also be used to follow-up postoperative patients which will be of immense help to those patients living in far flung areas and who might otherwise have been lost to follow-up.

4.4. Have a center of excellence as a mentoring institution

Developing a relationship with an established center goes a long way in guiding new programs. It has been suggested that it is important that they develop partnerships with successful programs that were built in RPCs who faced and overcame similar problems without taking recourse to expensive technology and enhanced manpower.[13] Unique problems are encountered in patients who present late in the course of their disease. Established centers in RPCs are better placed in dealing with these problems compared with similar programs in developed countries who may offer invaluable insight when addressing the larger picture but find themselves in unfamiliar grounds when dealing with the specifics. Established programs in RPCs can mentor smaller programs, by arranging visiting fellowships and allowing them to experience firsthand how leaders balance authority with mentoring, nurturing, and supporting their team to help achieve optimal outcomes.

4.5. Engage healthcare administrators

Without the help of healthcare administrators, it is impossible to start a CHD program. Healthcare administrators do not understand congenital cardiac care easily because it is a multidisciplinary and resource intensive specialty with unpredictable outcomes.[8] Healthcare administrators are necessary to help secure funding. They are also an essential partner in creating a culture of safety in which CHS can thrive.

4.6. Find alternate ways of funding

As a highly resource intensive specialty, CHS has remained at the bottom of the healthcare food chain in RPCs. Apart from involving and engaging healthcare administrators to procure vital funding, government subsidies, and contributions from charitable organizations can help reduce cost of care. At the sharp end of the spectrum, cost containment measures at preoperative, intraoperative, and postoperative levels can go a long way in making congenital cardiac care less expensive.[9]

5. Poor resources are not the only impediment

5.1. Build a culture of safety

CHS has poor error tolerance with a limited ability to retrieve poor outcomes. Of all the deaths in CHS, 20% are from preventable causes implying that error and human factors have a significant role to play in their causation.[16] CHS in its ideal form exists within a “culture of safety”.[17]

There is no doubt that continued investment and efficient maintenance of material infrastructure is essential to providing safe and quality care. However, providing quality care is also rooted in human factors, culture, and behavior.[18] Studies in high-income countries have established that it is wrong to assume that money is all that is needed to provide safe care. Improving patient safety requires attention not only to resource levels but to culture and organizational systems.[19] Quality care thrives in a “culture of safety”, and there is ample evidence in literature that a culture of safety is associated with positive outcomes such as reduced infection rates,[20] fewer readmissions better surgical outcomes,[21] reduced adverse events, and decreased mortality.[22]

It may be argued that the tools for building a “culture of safety” for patients have been predominantly developed in the healthcare systems of the west where material resources to support such initiatives are plenty. A “culture of safety” is defined as a product of individual and group beliefs, values, attitudes, perceptions, competencies, and patterns of behavior that determine an organization's commitment to quality and safety.[23] Culture is to a group what character and personality are for an individual.[24] Organizations that have a robust safety culture have an atmosphere of mutual trust and shared perceptions about safety.[25] Espousing and developing these characteristics is not dependent on material resources. These characteristics are created by a leadership that believes in and fosters these values. Safety culture in an organization is driven by its leadership who need to acknowledge that patient safety is a site of organizational and professional politics.[26] Individuals within the organization should have a collective mindfulness that safety is not a commodity but a value that requires continuous reinforcement.[27] Following is a review of important factors that contribute toward building a culture of safety, which have more to do with leadership than material resources:

5.2. Leaders lead by example

In CHD programs, the quality of leadership is of paramount importance. This is because leadership errors have a disproportionate effect on patient outcomes because of tight coupling and complexity of care. Leaders should prioritize safety and make it visible through their everyday actions. Efforts to improve safety need to be designed to take into account the realities of practice and should be based on an understanding of logics people are using to inform their practices.[26] It is a well-known fact that the “safety culture” concept was developed in high-risk organizations like the nuclear energy industry, airline industry, and aircraft carriers, where small errors in procedures and protocols can accumulate and lead to disastrous outcomes. The Institute of Nuclear Power Operations has defined 7 safety culture characteristics that are adaptable to leadership in the healthcare environment[24]:

1. Leaders demonstrate commitment to safety in their decisions and behaviors.
2. Decisions that support or affect safety are systematic, rigorous, and thorough
3. Trust and respect permeate the workforce.
4. Opportunities to learn about ways to ensure safety are sought out and implemented.
5. Issues potentially affecting safety are promptly identified, fully evaluated, and promptly addressed and corrected in order of their significance.
6. A safety conscious work environment is maintained where workers feel free to raise safety concerns without intimidation, harassment, discrimination, and fear of retaliation.
7. The process of planning and controlling work activities is implemented so that safety is maintained.

5.3. Nonpunitive approach

A transparent nonpunitive approach to reporting error and learning from adverse events is the hallmark of a safe organization. Workers at the sharp end of the spectrum should feel secure in the knowledge that when they report errors and unsafe conditions within the organization, their leadership will be supportive. Underreporting of error is a problem related to blame culture in medicine. In absence of reporting error, crucial data on error goes missing which predisposes the organization to repeat errors. This underlines the importance of developing a “culture of justice” within which a “culture of safety” thrives.[28] In a “just culture”, accountability is balanced with the need to openly acknowledge and address mistakes. It distinguishes between an honest mistake, risky behavior, and reckless behavior. An honest mistake can be dealt with by training of personnel or by process improvement if it happens because of a system error. Risky behavior can be dealt with by incentives or disincentives. Reckless behavior should be addressed by punitive measures.[29]

5.4. Address hierarchical dynamics

An important task of leaders is to address hierarchical dynamics. Hierarchical dynamics is an important determinant of team work. Elite groups like doctors feel that they can violate safety rules with impunity because they do not recognize those beneath them as having authority to sanction their conduct. Also, managers can be limited in their ability to control what staff does with the result that staff do not always follow safety protocols. Nonphysician staff commonly harbor feelings of not being held in enough esteem or being disrespected by medical staff which contributes to low morale and poor safety outcomes. Leaders must champion efforts to eradicate intimidating behaviors and make sure safety-related feedback from staff is acknowledged and implemented.[19] When team members know that they are respected and valued, they are able to engage more meaningfully in their work and deliver more effective and safer care.[30]

5.5. To sum it up

It is beyond the fiscal capabilities of RPCs to emulate the expensive technological advances and high maintenance manpower investments of the developed world which enables the latter to achieve outstanding results in treatment of CHD. But it is not unreasonable to believe that RPCs can produce leaders who espouse commitment to a safety-based culture built on trust, decisiveness, and learning behavior which creates a safety conscious working environment free of harassment, intimidation, and retaliation. In fact, this kind of leadership is relevant to all aspects of governance within RPCs.

Mumbai dabbawallas clearly demonstrate how a very low rate of error can be achieved at very low cost by a decentralized workforce that performs very efficiently in an environment that can at best be described as unpredictable. Five thousand dabbawallas distribute 130,000 lunch boxes through one of the most populous cities in the world making more than 260,000 transactions in 6 h, 6 days a week with an extremely low degree of error. They have a system that empowers people at the sharp end to report problems and take decisions. The workforce has a strong sense of belonging and psychological safety that leads to low error rates. They have devotion to their mission which is delivering food to people in time. The dabbawallas show that with the right system in place, an organization does not need huge material investment and extraordinary talent to achieve extraordinary results.[31]

The complexity of CHS is no doubt a very different ball game when compared with distributing lunch boxes. But, it can be safely argued that if a poorly educated work force can organize itself and develop a culture that is perfectly aligned and mutually reinforcing to a degree that they function with a very low degree of error,[31] it is absolutely possible for a team of highly educated and professionally trained people to create and sustain a “safe organizational culture”.

6. Conclusion

CHS is a resource intensive specialty. The western model of congenital cardiac care is too expensive to be sustainable in RPCs. Surgeons and physicians in RPCs should think innovatively to establish a tailored model within their limited resources. Congenital cardiac care thrives in a “culture of safety” which exists within a “culture of justice”. Creating a just and safe culture above all requires a leadership that is committed to delivering safe care. A leadership committed to safety creates conditions that enables clinicians, nurses, and allied staff to acknowledge and report errors without fear of harassment or retaliation and encourages them to strive collectively to achieve safe outcomes.

Declaration of competing interest

I have no conflict of interest to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.cmrp.2019.09.006.

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