180 Complexity of Caring for Complex Pediatric Congenital Heart Disease

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Abstract

The optimal care of pediatric patients with complex congenital heart disease requires collaboration and a multidisciplinary team approach from surgery, cardiology, anesthesiology, critical care, and other medical subspecialties. It is essential that an effectively functioning cardiac team be established in the care of complex congenital heart disease patients to reduce their morbidity and mortality. The vital components of a highly effective team not only include clinical excellence throughout all disciplines but must include excellence in leadership, trust, accountability, respect, and a shared mental model of the heart center's mission and values. If these components are maximized, the quality of patient care excels, optimizing the lives of children with congenital heart disease.

Keywords

Aristotle risk adjustment • Case volume • Collaboration • Congenital heart surgery database • Cost • Complexity • Developing countries • Economics • Functional teams • Integrated clinical pathways • Multidisciplinary • Quality of care • Quality improvement • RACHS-1 • Resource utilization • Risk adjustment • Simulation • Standardization • Teams • Team building • Team members • Team training • Transitions of care • Outcomes

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Introduction

Medical and surgical advances have allowed many complex, and formerly life-ending, congenital heart defects to be managed as a chronic illness. Examples of recent innovations in the care of complex congenital heart diseases (CHD) include (1) definitive repair in very low birth-weight neonates, (2) new surgical techniques (e.g., hybrid techniques, minimally invasive techniques), (3) improvement in infant and pediatric perfusion equipment and mechanical support devices (i.e., extracorporeal membrane oxygenation(ECMO) to manage refractory cardiorespiratory failure and aid cardiopulmonary resuscitation), (4) newer pharmacologic therapies (e.g., inhaled nitric oxide, natriuretic peptide, vasopressin, milrinone), (5) advances in imaging technology (e.g., cardiac MRI, transesophageal echocardiogram(TEE)), and (6) "state-of-the-art" monitoring modalities (e.g., cerebral oximetry) [1].

In the neonatal period, patients with CHD frequently require interventions and perioperative care that is highly complex and there is little physiologic tolerance for error. Moreover, there is a vast array of congenital and postsurgical anatomic variations and numerous possible palliative or reparative options to consider.

The optimal care of pediatric patients with complex congenital heart disease requires collaboration and a multidisciplinary team approach from surgery, cardiology, anesthesiology, critical care, other medical subspecialties, and multiple other professionals. Pediatric cardiac professionals greatly enhance functionality as a team and are limited as individual members. To obtain the greatest benefit for the child with CHD, all members of a pediatric cardiac team must be provided the opportunity to contribute their knowledge and skills and share the common vision of excellence in outcomes.

Decreasing mortality across institutions has led to the increased use of in-hospital morbidity and functional status as a relevant outcome measure following cardiac surgery for congenital heart disease. Functional, collaborative, and multidisciplinary teams work to further reduce mortality and morbidity for pediatric patients undergoing complex congenital heart surgery.

Multidisciplinary Nature of Care

A search of the websites of congenital heart disease programs in the United States frequently cite "team approach," "multidisciplinary approach," "integrated," "collaborative," "multiple experts," and "specialized knowledge" to describe the local pediatric cardiac team. Moreover, many programs state "management of the pediatric patient for congenital heart disease requires a multidisciplinary team approach." Such indications stress the importance of multidisciplinary care, yet do not always state why it is so valuable.

Patients with complex CHD are frequently very sick and require complex interventions while they are still in the fragile neonatal period. Collaboration, defined as professionals with different skill sets sharing knowledge and expertise in a positive working environment as they deliver health care, is required. Maternal-fetal specialists, neonatologists, pediatric cardiologists, pediatric cardiac surgeons, and others may be consulted to make an in utero diagnosis of CHD, prepare for delivery, and plan early palliative or corrective intervention. Preoperatively, palliative interventions may be undertaken by pediatric cardiologists and specialized imaging used by radiologists (i.e., cardiac MRI and MRA) and pediatric cardiologists (i.e., TEE, cardiac catheterization), often requiring the involvement of pediatric cardiac anesthesiologists.

In addition, multidisciplinary meetings are used to plan the necessary palliation or definitive repair with the pediatric cardiac surgeon and/or pediatric cardiology interventionalist. Newer techniques, such as the hybrid palliative strategy of pulmonary artery banding and ductal stenting for neonates with hypoplastic left heart syndrome (HLHS), involve multiple disciplines working seamlessly together. The cardiac surgeon, cardiac anesthesiologist, cardiologist, perfusionist, and specialized nurses and technicians work together as a multidisciplinary team during the intraoperative period. A "handoff" or transition of care is required as the patient is transferred from the operating room to the intensive care unit (ICU). In the ICU, a team mainly composed of cardiac intensivists, cardiologists, cardiac surgeons, nurse practitioners, bedside nurses, and many others including pediatricians, pharmacists, respiratory therapists, nutritional therapists, occupational therapists, physical therapists, social workers, child life experts, and multiple support staff provide care for the patient. Residual problems following corrected CHD (e.g., arrhythmias, ventricular dysfunction, arterial-pulmonary or veno-caval shunts, valve stenosis or regurgitation, pulmonary hypertension) may require further interventions and collaborative team efforts.

Good outcomes depend on well developed and mature collaborative teams working together and many complex systems functioning smoothly. However, the contribution of each member of the multidisciplinary team on outcomes has not been well evaluated in the realm of pediatric cardiac care. Most research has focused on surgeon performance and mortality as a single outcome. However, in some cases, mortality may be strongly influenced by patient and postoperative management factors, rather than technical outcomes of the procedure itself. The contribution of other team members (e.g., anesthesiology, cardiology, intensive care teams) towards errors in diagnosis, decision-making, and communication has not been well investigated. Recently, the relationship of nurse staffing, skill mix, and Magnet recognition to institutional volume and mortality for congenital heart surgery was examined in almost 20,000 cases and at 38 children's hospitals. Interestingly, none of the nursing characteristics was associated with mortality. The authors postulated the outcome variable of mortality might be insensitive to nursing characteristics in children's hospitals, as long as certain staffing thresholds have been met [2].

More patients with congenital heart disease are reaching adulthood, resulting in a changing profile of congenital heart disease. In 2000, the number of adult congenital heart disease patients was approximately equal to the number of pediatric congenital heart patients. In 2020, adult pediatric CHD patient population is projected to far exceed the pediatric CHD patient population [3, 4]. Multidisciplinary teams with specialized knowledge and training in adult CHD management will be needed, as residua and sequelae frequently complicate reparative surgery and require long-term surveillance and further intervention. The care of individuals with complex heart defects must be continuous through life and provided by multidisciplinary teams.

The Pressures of a Rapidly Evolving Health Care: Outcomes, Quality, and Economics

Outcomes

Although mortality is the ultimate outcome variable, analysis of this variable is limited to only approximately 4 % of the total pediatric congenital heart surgery population [5]. Current published estimates of mortality rates for children and infants undergoing cardiac surgery vary from 3.7 % to 4.3 %, while mortality rates for individual cardiac procedures based on type and procedural complexity range from 0 % to 30 % [6, 7]. The use of in-hospital morbidity, rather than mortality alone, and functional status as an appropriate outcome measure following cardiac surgery for congenital heart disease is in its infancy [8, 9].

There is significant inter-institutional variation in mortality after congenital heart surgery, and there are limitations of using in-hospital mortality rates as a basis for quality measurement or comparison. Mortality rates are "too low," and pediatric cardiac surgery is performed too infrequently and with a high number of operation types, to allow valid quality comparisons between programs based on in-hospital mortality [5, 10]. There also appears to be racial and ethnic disparity in mortality rates. Racial/ethnic minority groups have greater risks than white children for death after congenital heart defect surgery and an earlier median age at death for those with congenital heart defects [11]. Hence, mortality rate alone is not a valid indicator of quality differences between pediatric cardiac surgical programs.

Case Complexity

Mortality increases as complexity of the pediatric cardiac surgical procedure performed increases. An institution or program that does predominantly atrial septal defect (ASD) repairs would not be expected to have a similar mortality rate as a program or institution that performs predominantly complex congenital heart surgical procedures or interventions including Norwood staged procedures. Therefore, using raw data such as measurements of mortality without adjustment for complexity is inadequate. Quality of care and outcome evaluations must take into account variations in case complexity or "case mix" [5, 12].

Comparing mortality rates between institutions/programs that have varied case mixes requires the use of complexity-based "risk adjustment" methods. Two common ways of performing risk adjustment in congenital heart surgery include the RACHS-1 (Risk Adjustment in Congenital Heart Surgery-1) and Aristotle methods [13, 14]. As complexity increases in both the RACHS-1 and Aristotle methods of assessing complexity, discharge mortality increases. Both RACHS-1 and Aristotle risk adjustment methods are used to facilitate complexity stratification in databases such as the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database. Risk adjustment may perhaps be used in assessing local risk-adjusted results for CHD lesions and using evidence-based referral to other centers with lower risk-adjusted mortality for specific CHD pathology [15].

Case Volume

Most studies of the volume-outcome relationship have reported significant associations between higher case volume and better health outcomes for many types of surgical procedures. However, the relationship between pediatric cardiac surgical volume and mortality is not straightforward. Larger case volumes cannot automatically be equated with better quality of care. With adjustment for patient-level risk factors and surgical case mix, there appears to be an inverse association between pediatric cardiac surgical volume and mortality that becomes increasingly important as case complexity increases. When comparing mortality for low-complexity cases, volume was not associated with mortality; however, when case complexity increased, lower-volume programs underperformed larger volume programs. Small was defined as yearly pediatric cardiac surgical volume <150; medium, 150–249; large, 250–349; and very large, ≥ 350 cases [16].

Evidence-Based Practice, Variability, and Quality

As clinical outcomes in CHD have improved in recent years and mortality rates have decreased, measurements of quality and outcome have moved away from mortality alone towards reducing morbidity and improving functional outcomes. Quality improvement science has demonstrated that standardization of practices is associated with cost savings and improved operating efficiency. Reducing process variation through the standardization of common practices results in more favorable outcomes. However, there still remains considerable institutional and individual variation in the management of pediatric patients with complex CHD.

Although practice should be driven by evidence, there currently exists a large gap in knowledge on the impact that everyday decisions have on the surgical management and outcome of patients with CHD [17]. There is great variability in the patients, as well as many aspects of the management of patients with CHD, that makes standardized assessment and comparison of outcomes between programs or institutions difficult. There are multiple possible types of interventional/surgical procedures that vary in complexity and mortality rates, multiple anatomic variants of specific CHD lesions, and multiple associated abnormalities that increase morbidity or mortality that might be present in some patients but not others. Moreover, there is considerable individual practitioner and institutional variability as well as inter-institutional variation in the post-operative course and management of patients based on specific CHD pathology, whether post-operative care is provided in a dedicated pediatric cardiac ICU, whether a pediatric cardiac intensivist is present in house 24/7, among other patient-care variables [17–20].

The National Heart, Lung, and Blood Institute established the Pediatric Heart Network in 2001 to provide a collaborative network for conducting clinical studies in an attempt to provide the evidence needed to drive evidence-based practice. Recent advances include the formation of working groups to help identify and define the areas in which clinical studies might have the greatest impact, clinical registries and databases (i.e., STS Congenital Heart Surgery Database) for researching outcomes, and large multi-institutional research and quality improvement collaborations to assist in reducing clinical process variation and improving patient outcomes [17, 18]. Quality improvement projects could include multidisciplinary site visits between institutions to discover both variability and commonality in practice, allow sharing of information about successes, and compilation of successful practice changes as a route to better outcomes [21].

Cost/Economics

Across the world, approximately one million children per year are born with congenital heart disease, but approximately 90 % of these receive suboptimal care or no care at all. Childhood CHD mortality is very high in low-income countries, and only a small number benefit from surgical treatment. Problems with care of those with CHD in developing countries include (1) a large number of children with congenital heart defects, (2) delay in diagnosis and late presentation, (3) prioritizing patients with congenital cardiac malformations for cardiac surgical procedures when resources are limited, (4) difficulty maintaining quality care, including training caregivers, (5) and determining the best procedure to achieve maximum palliation at lower cost, as less than 5 % can afford surgery [22–25].

Congenital heart disease affects nearly 1 % of all live births and consumes an estimated six billion dollars annually in acute care costs alone. Although the incidence of CHD has remained stable during the last 50 years, the natural history of most lesions has changed quite dramatically [26]. In developed countries of the world, approximately 90 % of infants with CHD survive into adulthood, and the focus has changed from an emphasis on reducing perioperative mortality to improving quality of life and reducing morbidity [27]. Those with CHD are living longer. These patients will require interventions, have complications, and may need more than one operation. As the life expectancy for adults with CHD increases and diagnostic and therapeutic options continue to evolve, significant resources will be required to care for this patient population [4].

There is limited data regarding factors impacting resource utilization for patients undergoing congenital heart surgery. Hospital discharge data from the year 2000 including 10,569 cases of congenital heart surgery in patients <18 years of age from 27 states identified median total hospital *charges* per patient of $53,828. Those patients with charges in the uppermost decile for total hospital charges (i.e., exceeding $192,272) were designated as high resource users. Independent predictors of a higher odds of high-cost cases included risk adjustment for congenital heart surgery risk category, age, prematurity, the presence of other major non-cardiac structural anomalies, Medicaid insurance, and admission during a weekend. Gender, race, bed size, teaching and children's hospital status, hospital ownership, and hospital volume of cardiac cases were not independently associated with greater odds of high resource utilization. There was some geographic variation in resource utilization between states [28].

In a more recent investigation, patients 0–18 years of age undergoing congenital heart surgery and surviving to hospital discharge ($n = 2124$) between 2001 and 2007 at a large number of hospitals utilizing a specific database system were studied. The median unadjusted total hospital *cost* per patient for four specific CHD lesions was as follows: ASD repair ($12,761), VSD repair ($18,834), tetralogy of Fallot repair ($28,223), and arterial switch operation ($55,430). For each of the four surgeries, room and board accounted for the largest proportion of total costs (≈33–40 %). Interestingly, total hospital costs varied significantly by center for all congenital heart surgeries evaluated, even after adjustment for patient and center characteristics and length of stay. The differences among centers were most prominent for lower-complexity procedures, suggesting that strategies to reduce cost variation may be best focused on lower-complexity, common CHD operations [29]. However, most would agree that higher complexity justifies higher reimbursement. There is a known positive correlation between in-hospital costs and Aristotle scores, and the Aristotle score or complexity score could be used to match reimbursement with the clinical complexity of the disease or condition [30].

Evidence should be used to drive change when attempting to reduce costs and improve quality in the care of children with CHD. Several areas that have been investigated for which there is at least some data to help guide therapy include (1) evidence-based referral of patients to the most appropriate centers for care, (2) cost-effective use of salvage cardiac ECMO in children with CHD, (3) cost-effective use of TEE during pediatric cardiac surgery, and (4) appropriate use of "fast-tracking" defined as the concept of early extubation, mobilization, and hospital discharge, in an attempt to improve outcome [15, 31–33].

Complications (e.g., postoperative infection, hemorrhage complicating a procedure, iatrogenic pneumothorax) are associated with higher resource utilization. In one study, those with complications were three times more likely to exceed $192,272 in total charges (uppermost decile of charges), despite adjusting for known risk factors for high resource use [34]. Complication reduction is likely to result in economic benefit. If a health-care system permits institutions to charge for each hospital day, postoperative procedure, and complication that prolongs hospital stay, it is paradoxically financially rewarding institutions with poor outcomes. Reimbursement in the future should be designed to reward institutions with better "surgical performance" for equal or greater complexity care.

In reality, medicine may be able to provide more care than society can afford. A discussion of financial cost should include long-term psychosocial and societal economic "costs" [9, 35]. Future discussions of cost need to move beyond the costs of in-hospital care [36]. Maintaining cost-effective care requires (1) evidence-based and timely referral, (2) early surgical correction, (3) adequate postoperative care provided in an evidence-based manner, and (4) reduction of complications. Innovation and effective team building are also necessary to cut costs and improve the quality of care.

The Importance of Teamwork in the Care of the Complex and Fragile Child

> The major benefits of a team concept occur only when all involved have a chance to exert their skills, knowledge, and influence.
> –Gregory E. Huszco (Tools for Team Leadership 2004)

> Perhaps the most significant requirement for creation of a cohesive team is in creating a collective sense of responsibility towards the patient.
> –PK Kumar (Ann Pediatr Cardiol 2009)

> The patient is the star, not you.
> –R Schell, M.D.

Multidisciplinary Teams

Minimizing the financial costs of providing care to children with CHD that is innovative and effective, yet efficient and cost-effective, will require teams whose individual members are allowed – and encouraged – to contribute their individual discipline-specific expertise. Innovations in technology, growth in knowledge, and improved interdisciplinary collaboration have contributed to improved outcomes in CHD.

The development of pediatric cardiac subspecialties in cardiology, surgery, anesthesiology, and intensive care, among others, has increased the number of highly trained professionals with unique knowledge and skills. In the optimal setting, these subspecialists work as a cohesive team that effectively communicates, collaborates, and cooperates. In this multidisciplinary team approach, each member of the team has both an opportunity and obligation to exert their skills, knowledge, and influence towards a common vision of excellence in outcomes. A model based on one professional being the "captain of the ship" and other professionals following orders is antiquated and suboptimal for managing patients with complex CHD.

In the past, roles have been quite compartmentalized. The pediatric cardiologist made a diagnosis and referred the child with CHD to a cardiac surgeon who performed the requested surgery, and the patient was cared for by the cardiac surgeon in a pediatric intensive care unit, not specifically dedicated to pediatric cardiac patients, and followed up by pediatric cardiology.

There has been a blurring of the distinction between individual specialties and defined specialty roles and increased recognition that pediatric cardiac care thrives on teamwork. Innovations in technology, increased complexity of disease, and evolving therapeutic strategies have driven this change. Examples include (1) increased available choices for methods of correction or palliation (i.e., surgical or catheter interventions, hybrid heart procedures) with individualized treatment plan determined by a multidisciplinary team; (2) requirement for correction in the newborn period or infancy; (3) newer imaging modalities, such as TEE, that contribute to the team approach when anesthesiologists and pediatric cardiologists provide insights that the pediatric cardiac surgeon seeks, including immediate postoperative assessment of repair; and (4) pediatric cardiac intensive care management by a multidisciplinary team in a dedicated pediatric cardiac intensive care unit [1, 19, 37, 38].

Although cardiac surgical skill deficiencies may be more immediately visible to those evaluating overall program quality and outcomes, deficiencies in other members, though often more subtle, may become apparent over time. Significant incompetence in one area of the multidisciplinary team can result in the whole team becoming dysfunctional and ultimately compromising patient care.

Characteristics of Functional Teams

By definition, a team is "a number of persons associated in some joint action," while functional refers to that team's ability to perform a regular function. When referring to teamwork in pediatric heart care, Kumar states, "Establishment of a cohesive team requires organization of a group of team members with diverse skills to come together through good mutual understanding, under a leadership that actively promotes team harmony" [39].

The Accreditation Council for Graduate Medical Education's (ACGME) six general competencies can be incorporated into the definition of a well-functioning team. Members of a functional team would, individually and collectively, provide excellent patient care and have an in-depth knowledge of pediatric congenital heart disease as it relates to their subspecialty as well as that of others. In addition, they would have excellent interpersonal and communication skills, exhibit professionalism, have a good understanding of the system they work in (systems-based practice), and continuously try to improve individual as well as collective knowledge, skills, and attitudes (practice-based learning and improvement).

Huszczo describes seven components of excellent teams in organizations. He follows in a later publication adding the X-factor in whether a team succeeds, that being leadership.

Components of Excellent Teams

- Clear goals and sense of direction
- Identification of talent
- Clear roles and responsibilities
- Agreed-upon procedures
- Constructive interpersonal relations
- Active reinforcement of team-oriented behaviors

- Diplomatic external ties
- Effective Leadership

Clear goals and objectives allow the team, and the organization, to know why it exists and what it is to accomplish. Individuals that are skilled and talented are needed in key team positions (i.e., pediatric cardiology, pediatric cardiac surgery, pediatric cardiac anesthesiology, pediatric cardiac intensive care, pediatric cardiac nursing). All members should have clear understanding of each team member's role and responsibilities. One way to improve the process of understanding each team member is to develop an interest in each other's specialty. For example, the pediatric cardiac anesthesiologist who attends pediatric cardiology conferences and learns more about echocardiographic imaging in CHD will better understand the role of the pediatric cardiologist. The pediatric cardiologist who spends time in the operating room observing the pediatric cardiac surgeon operate and the process of separating from cardiopulmonary bypass will have a better understanding of the role of the surgeon, perfusionist, and anesthesiologist. Teams that have agreed-upon procedures and who have worked together to establish patient-care protocols and standardization of perioperative management in an attempt to reduce variability would be expected to have better outcomes. As well, constructive interpersonal relations are fostered by good communication. Disagreements, which are inevitable, should not be left to fester but be resolved quickly, in an open, transparent manner and in an environment of trust and mutual respect. Team-oriented behaviors are reinforced when all members of the team have the opportunity to exert their skills and knowledge. One example of this is a weekly team meeting for preoperative collective decision-making and planning of specific strategy and to anticipate and prepare for perioperative issues. Diplomatic "external ties" are required for the team to effectively work within an organization and also to maintain an active referral system. Moreover, team leadership is a key component of functional teams. It is often necessary to have many individual leaders in different areas working together to help the team move forward, but there is usually a single key leader. Team leaders should encourage harmony, influence but not control team members, help the team make an accurate assessment of its actions (i.e., sharing patient outcomes) and structure, facilitate consensus decisions, and push the team to operationalize the ideas they generate.

Team Building

Team building can be defined as "a continuous process to apply some systematic approach to getting people to work together successfully." This definition implies that team building in pediatric cardiac surgery is much more than one or several events designed to develop camaraderie but rather is a continuous, intentional, and systematic process.

Important aspects of teams and teambuilding in pediatric cardiac surgery teams have recently been reviewed [39].

1. *Understand Each Other's Role*
   As mentioned above, it is important that each member of the team has an understanding of each other's role in the team and this should be encouraged. The pediatric cardiologist spending time in the operating room observing the technical process and decision-making of the pediatric cardiac surgeon serves such a purpose.
2. *Maintain Clear Communication*
   Clear communication between team members at all times, and especially at critical junctures in patient care such as "handoffs" or transition in care, is essential. Forms of communication include verbal between team members, written documentation on records, group meetings where outcomes are reviewed, and family meetings where family members are kept informed of all aspects of patient care.
3. *Address and Resolve Disagreements*
   It is inevitable that a team of highly educated and diversely trained caregivers will have occasional disagreements. A team made up of individuals who trust each other, communicate well, and have mutual respect will resolve disagreements rapidly, transparently, and amicably. Disagreements that are not resolved this

way may lead to fractured relationships, dysfunctional teams, and negative impacts on patient outcome.

4. *Encourage Collective Decision-Making*
Forums such as multidisciplinary patient rounds, monthly quality improvement meetings, and pre-intervention patient management meetings provide the opportunity for each team member to exert their skills, knowledge, and influence so that decisions are made collectively and in the patient's best interest.
5. *Recognize Individual Team Member Roles*
Cohesive and functional teams have a collective sense of responsibility towards the patient. While individual roles may vary in their importance to overall program success, leadership must recognize the contributions of individual members of the team. This includes the nursing staff at the bedside, resident physicians, catheterization laboratory technicians, and others, as well as the more highly visible team members. Leadership that privately and publicly recognizes individual members will more likely have a motivated team that is working in harmony towards the common goal of excellent patient outcomes.
6. *Regular Review of Team Performance*
It is relatively easy to collect annual mortality data as a measure of performance and focus the review of team performance on the highly visible members, such as the pediatric cardiac surgeon. However, a functional team will perform collective introspection at regular specified intervals. These responsibilities should be performed within each discipline in formal performance improvement programs and reporting to an oversight committee of heart center leaders. These reviews examine morbidities as well as mortality to correct substandard systems processes.

Team Best Practices and Team Training

Examples of best practices in pediatric cardiac teams and training include regular multidisciplinary planning conferences, multidisciplinary cardiac surgery rounds, a dedicated pediatric cardiac intensive care unit, integrated clinical pathways, effective and safe transitions in care, ongoing continuous evaluation and review, and the use of simulation and crew resource team training.

1. *Regular Multidisciplinary Planning Conferences*
There is a wide variability in congenital cardiac disease anatomic variation and presentation. Moreover, there are multiple palliative or definitive interventions to consider. Utilization of multidisciplinary planning conferences where input from all members of the multidisciplinary pediatric cardiac team is obtained prior to intervention is an example of a best practice.
2. *Multidisciplinary Pediatric Cardiac Surgery Rounds*
The American College of Critical Care Medicine recommends the availability of a multidisciplinary team and a full-time intensivist as a way to "improve outcomes as measured by reduced mortality, improved efficiency, decreased length of stay or decreased cost of care" [40]. Multidisciplinary rounds in the critical care environment have demonstrated a reduction in medical errors, cost savings, and increased communication [37, 41]. Members of the multidisciplinary cardiac surgery rounds include the pediatric cardiac surgeon, pediatric cardiac intensivist, acute care pediatric nurse practitioners, pediatric cardiac nursing staff, clinical pharmacist, and clinical respiratory technician, among others [38, 42]. One study of multidisciplinary rounds of cardiac patients in a pediatric intensive care emphasized the need for more evidence regarding the effectiveness of this approach and the need to shorten data retrieval and presentation time and focus more on decision-making, discussion, and teaching [37].
3. *Dedicated Pediatric Cardiac Intensive Care Unit*
Most high-volume centers (>350 surgical cases/year) have dedicated pediatric cardiac intensive care units. In France, pediatric cardiac surgery programs approved by the French Health Ministry must perform at least

"150 major operations per year in children" and must provide a "specialized pediatric intensive care unit." In one study, a dedicated pediatric cardiac intensive care unit was associated with a decrease in morbidity (i.e., wound infections, need for chest re-exploration) and less need for resuscitation as well as decreased mortality [19]. Dedicated pediatric cardiac intensive care units have shown better outcomes in terms of earlier extubation, de-intensification, and discharge from the ICU. Bloodstream infections are also reduced [43].

Optimally, pediatric cardiac intensive care programs should have patients (preoperative and postoperative) grouped together geographically and in close proximity to the operating room, catheterization laboratory, radiology department, and regular ward. Also important are dedicated age-appropriate equipment and strategies [20].

4. *Integrated Clinical Pathways*
Marked institutional and individual variability exists in the care of pediatric cardiac patients [17, 44]. The concept of integrated clinical pathways refers to development and attempts to utilize evidence-based standardized care throughout the pediatric heart patient's intervention and hospitalization especially for the more complex anomalies (i.e., hypoplastic left heart syndrome and staged repairs).

5. *Effective and Safe Transitions in Care*
Transitions in care, or "handoffs," may require physical movement of equipment and technology, sharing of patient information, and transfer of responsibility for care of the patient. The ACGME recently recognized the importance of transitions in patient care and made training and documentation of such a residency training a requirement.

The care of infants after complex congenital heart surgery and "handoff" of care from the surgical team to the intensive care team after intervention is an especially vulnerable period for errors. Components identified as critical to the successful handover of a patient to the ICU include (1) efficient transfer of monitors and equipment, (2) limiting discussions to those related to the patient, (3) face-to-face sharing of patient information, (4) discussion of care plan with all providers involved, and (5) limiting interruptions during the information handoff. A formal standardized multidisciplinary protocol handover process for pediatric cardiac patients transitioning to the intensive care unit after cardiac surgery can mitigate human error, help prevent patient harm, and improve teamwork among caregivers [45].

Standardized multidisciplinary handover protocols, including ones that utilize Formula 1 pit-stop and aviation models, have improved the safety and quality of the handover process [46]. In this model, the anesthesiologist is given overall responsibility for coordinating the team, and this is transferred to the pediatric cardiac intensivist at the completion of the handover. The anesthesiologist completes a standardized transfer form at least 30 min before transfer of the patient to the pediatric cardiac intensive care. The handover includes three major components: (1) equipment and technology, (2) information, and (3) discussion and plan with allocated tasks for each caregiver, including nurse and respiratory technician. Communication is limited to essential conversations during handoff where the anesthesiologist and surgeon speak uninterrupted. This is followed by a printed handover protocol process and a task sequence and checklist with task allocation known and observed by team members. Although the anesthesiologist and intensivist have responsibility for situational awareness at handover and regularly step back and make safety checks, all "crew members" are encouraged and trained to speak up if issues are identified.

6. *Ongoing Continuous Evaluation and Review*
The pediatric cardiac program should make every attempt to study and improve all aspects of patient care. This should include a multidisciplinary quality improvement process and a mechanism for longitudinal follow-up of patients and outcomes.

7. *Work and Train Together as a Team*
Effective multidisciplinary teams often work and train together. Resuscitation of pediatric

cardiac patients requires multidisciplinary collaboration and teamwork. Simulation-based Crisis Resource Management (CRM) training has been utilized to improve preparedness and decrease anxiety among multidisciplinary resuscitation teams [47]. Situations in which team training utilizing simulation might be helpful include crisis resource management, failure to separate from cardiopulmonary bypass, rapid deployment or emergent ECMO, and transitions in care. Simulation might also be utilized to reinforce training and evaluate performance. However, whether participation in a pediatric cardiac intensive care CRM training program improves team function during real resuscitation is unproven.

Examples of Pediatric Cardiac Team "Best Practices"

1. Utilize regular multidisciplinary planning conferences.
2. Utilize multidisciplinary pediatric cardiac surgery rounds.
3. Provide a dedicated pediatric cardiac intensive care unit.
4. Develop and follow evidence-based integrated clinical pathways.
5. Provide effective and safe transitions in care.
6. Perform ongoing continuous evaluation and review of program.
7. Work and train together as a team.

Team Performance

Team performance improvement should focus on issues rather than on individuals and reporting of morbidity encouraged with review of morbidity and mortality accomplished in a nonjudgmental manner. Although at times specific contributors (e.g., providers or systems issues) to morbidity and mortality need to be identified precisely, the focus should be on collective team performance, reducing variability, and improving outcomes.

Factors that might impede team performance include (1) ego of individuals often evidenced by the attitude "I am right and all others are not"; (2) serious inequities in recognition, salaries, and rewards; (3) inability to "find time" to accomplish multidisciplinary meetings where all are encouraged to contribute to the team effort; and (4) leadership that does not encourage all team members to be involved in decision-making processes, protocols, and change management [39].

Quality improvement processes should be used to reduce clinical process variation and expand clinical networks, using data for research and improvement (i.e., STS Congenital Heart Surgery Database), resulting in better outcomes and generating new knowledge [17, 44, 48]. Both internal and external peer review of the program may provide insights and examples of how to improve care [42].

References

1. Bronicki RA, Chang AC (2011) Management of the postoperative pediatric cardiac surgical patient. Crit Care Med 39:1974–1984
2. Hickey P, Gauvreau K, Connor J et al (2010) The relationship of nurse staffing, skill mix, and Magnet® recognition to institutional volume and mortality for congenital heart surgery. J Nurs Admin 40(5):226–232
3. Webb GD (2001) Care of adults with congenital heart disease – a challenge for the new millennium. Thorac Cardiovasc Surg 49:30–34
4. Opotowsky AR, Siddiqi OK, Webb GD (2009) Trends in hospitalizations for adults with congenital heart disease in the U.S. J Am Coll Cardiol 54:460–467
5. Jacobs JP, Jacobs ML, Lacour-Gayet FG et al (2009) Stratification of complexity improves the utility and accuracy of outcomes analysis in a multi-institutional congenital heart surgery database: application of the Risk Adjustment in Congenital Heart Surgery (RACHS-1) and Aristotle Systems in the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database. Pediatr Cardiol 30:1117–1130
6. Thiagarajan RR, Laussen PC (2011) Mortality as an outcome measure following cardiac surgery for congenital heart disease in the current era. Pediatr Anesth 21:604–608
7. O'Brien SM, Clarke DR, Jacobs JP et al (2009) An empirically based tool for analyzing mortality associated with congenital heart surgery. J Thorac Cardiovasc Surg 138:1139–1153
8. Geyer S, Norozi K, Zoege M et al (2007) Life chances after surgery of congenital heart disease: the influence of cardiac surgery on intergenerational social mobility. A comparison between patients and general

population data. Eur J Cardiovasc Prev Rehabil 14(1):128–134
9. Nieminen H, Sairanen H, Tikanoja T et al (2003) Long-term results of pediatric cardiac surgery in Finland: education, employment, marital status, and parenthood. Pediatrics 112:1345–1350
10. Welke KF, Karamlou T, Ungerleider RM et al (2010) Mortality rate is not a valid indicator of quality differences between pediatric cardiac surgical programs. Ann Thorac Surg 89:139–146
11. Flores G (2010) Technical report – racial and ethnic disparities in the health and care of children. Pediatrics 125:e979–e1020
12. Jacobs JP, Lacour-Gayet FG, Jacobs ML et al (2005) Initial application in the STS Congenital Database of complexity adjustment to evaluate surgical case mix and results. Ann Thorac Surg 79:1635–1649
13. Jenkins KJ, Gauvreau K (2002) Center-specific differences in mortality: preliminary analyses using the Risk Adjustment in Congenital Heart Surgery (RACH-1) method. J Thorac Cardiovasc Surg 124:97–104
14. Lacour-Gayet F, Clarke D, Jacobs J et al (2004) The Aristotle score: a complexity-adjusted method to evaluate surgical results. Eur J Cardiothorac Surg 25:911–924
15. Allen SW, Gauvreau K, Bloom BT et al (2003) Evidence-based referral results in significantly reduced mortality after congenital heart surgery. Pediatrics 112:24–28
16. Welke KF, O'Brien SM, Peterson ED et al (2009) The complex relationship between pediatric cardiac surgical case volumes and mortality rates in a national clinical database. J Thorac Cardiovasc Surg 137:1133–1140
17. Kaltman JR, Andropoulos DB, Checchia PA et al (2010) Report of the Pediatric Heart Network and National Heart, Lung, and Blood Institute Working Group on the perioperative management of congenital heart disease. Circulation 121:2766–2772
18. Baker-Smith CM, Neish SR, Klitzner TS et al (2011) Variation in postoperative care following stage I palliation for single-ventricle patients: a report from the Joint Council on Congenital Heart Disease national Quality Improvement Collaborative. Congenit Heart Dis 6:116–127
19. Eldadah M, Leo S, Kovach K et al (2011) Influence of a dedicated paediatric cardiac intensive care unit on patient outcomes. Nurs Crit Care 16:281–286
20. Fraisse A, Le Bel S, Mas B et al (2010) Paediatric cardiac intensive care unit: current setting and organization in 2010. Arch Cardiovasc Dis 103:546–551
21. Welke KF, Diggs BS, Karamlou T et al (2008) Measurement of quality in pediatric cardiac surgery: understanding the threats to validity. ASAIO J 54:447–450
22. Holzer R, Ladusans E, Kitchiner D et al (2006) Prioritization of congenital cardiac surgical patients using fuzzy reasoning – a solution to the problem of the waiting list? Cardiol Young 16:289–299
23. Doherty C, Holtby H (2011) Pediatric cardiac anesthesia in the developing world. Pediatr Anesth 21:609–614
24. Mocumbi AO, Lameira E, Yaksh A et al (2011) Challenges on the management of congenital heart disease in developing countries. Int J Cardiol 148:285–288
25. Rao SG (2007) Pediatric cardiac surgery in developing countries. Pediatr Cardiol 28:144–148
26. Hoffman JIE, Kaplan S (2002) The incidence of congenital heart disease. J Am Coll Cardiol 39:1890–1900
27. Talwar S, Choudhary SK, Airan B et al (2008) Reducing the costs of surgical correction of congenitally malformed hearts in developing countries. Cardiol Young 18:363–371
28. Connor JA, Gauvreau K, Jenkins KJ (2005) Factors associated with increased resource utilization for congenital heart disease. Pediatrics 116:689–695
29. Pasquali SK, Sun J-L, d'Almada P et al (2011) Center variation in hospital costs for patients undergoing congenital heart surgery. Circ Cardiovasc Qual Outcomes 4:306–312
30. Sinzobahamvya N, Photiadis J, Arenz C et al (2010) Congenital heart surgery: applicability of hospital reimbursement according to German Diagnosis-Related Groups System in conformity with the Aristotle Complexity Score. Thorac Cardiovasc Surg 58:328–332
31. Mahle WT, Forbess JM, Kirshbom PM et al (2005) Cost-utility analysis of salvage cardiac extracorporeal membrane oxygenation in children. J Thorac Cardiovasc Surg 129:1084–1090
32. Bettex DA, Pretre R, Jenni R et al (2005) Cost-effectiveness of routine intraoperative transesophageal echocardiography in pediatric cardiac surgery: a 10-year experience. Anesth Analg 100(5):1271–1275
33. Mittnacht AJC, Hollinger I (2010) Fast-tracking in pediatric cardiac surgery – the current standing. Ann Card Anaesth 13(2):92–101
34. Benavidez OJ, Connor JA, Gauvreau K et al (2007) The contribution of complications to high resource utilization during congenital heart surgery admissions. Congenit Heart Dis 2:319–326
35. Kovacs AH, Sears SF, Saidi AS (2005) Biopsychosocial experiences of adults with congenital heart disease: review of the literature. Am Heart J 150:193–201
36. Williams WG (2010) Congenital heart disease: interrelation between German diagnoses-related groups system and Aristotle complexity score. Eur J Cardiothorac Surg 37:1271–1277
37. Cardarelli M, Vaidya V, Conway D et al (2009) Dissecting multidisciplinary cardiac surgery rounds. Ann Thorac Surg 88:809–813
38. Okuhara CA, Faire PM, Pike NA (2011) Acute care pediatric nurse practitioner: a vital role in pediatric cardiothoracic surgery. J Pediatr Nurs 26:137–142
39. Kumar RK (2009) Teamwork in pediatric heart care. Ann Pediatr Cardiol 2(2):140–145

40. Brilli RJ, Spevetz A, Branson RD et al (2001) Critical care delivery in the intensive care unit: defining clinical roles and the best practice model. Crit Care Med 29:2007–2019
41. Dunn EJ, Mills PD, Neily J et al (2007) Medical team training: applying crew resource management in the Veterans Health Administration. Jt Comm J Qual Patient Saf 33:317–325
42. Chang AC (2005) Common problems and their solutions in paediatric cardiac intensive care. Cardiol Young 15(1):169–173
43. Balachandran R, Nair SG, Gopalraj SG et al (2011) Dedicated pediatric cardiac intensive care unit in a developing country: does it improve the outcome? Ann Pediatr Cardiol 4(2):122–126
44. Kugler JD, Beekman RH, Rosenthal GL et al (2009) Development of a pediatric cardiology quality improvement collaborative: from inception to implementation. From the Joint Council on Congenital Heart Disease Quality Improvement Task Force. Congenit Heart Dis 4:318–328
45. Joy BF, Elliott E, Hardy C et al (2011) Standardized multidisciplinary protocol improves handover of cardiac surgery patients to the intensive care unit. Pediatr Crit Care Med 12:304–308
46. Catchpole KR, De Leval MR, McEwan A et al (2007) Patient handover from surgery to intensive care: using Formula 1 pit-stop and aviation models to improve safety and quality. Pediatr Anesth 17:470–478
47. Allan CK, Thiagarajan RR, Beke D et al (2010) Simulation-based training delivered directly to the pediatric cardiac intensive care unit engenders preparedness, comfort, and decreased anxiety among multidisciplinary resuscitation teams. J Thorac Cardiovasc Surg 140:646–652
48. Galvan C, Bacha EA, Mohr J et al (2005) A human factors approach to understanding patient safety during pediatric cardiac surgery. Prog Pediatr Cardiol 20:13–20