Ten year Clinical Experience of Humanitarian Cardiothoracic Surgery: Building a Platform for Ultimate Sustainability in a Resource-Limited Setting

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Abstract

Objective: Despite its near complete eradication in resource-rich countries, rheumatic heart disease (RHD) remains the most common acquired cardiovascular disease in sub-Saharan Africa. With a ratio of physicians/population of 1/10,500—including only 5 cardiologists for a population of 11.4 million, Rwanda represents a resource-limited setting lacking the local capital to detect and treat early cases of Strep throat and perform life-saving operations for advanced RHD. Humanitarian surgical outreach in this region can improve delivery of cardiovascular care by providing sustainability through mentorship, medical expertise, training, and knowledge transfer; and, ultimately, the creation of a cardiac center.

Methods: We describe the experience of consecutive annual visits to Rwanda since 2008 and report outcomes of a collaborative approach to enable sustainable cardiac surgery. The Ferrans and Power Quality of Life Index (QLI) tool-Cardiac Version (http://www.uic.edu/orgs/qli/) was administered to assess postoperative quality of life.
**Results:** Ten visits have been completed, performing 149 open procedures—including 200 valve implantations [NYHA class III or IV] with 3% 30-day mortality (Table 2). All procedures were performed with participation of local Rwandan personnel, alongside expatriate physicians, nurses, residents and support staff. Early complications included CVA (n=3), hemorrhage requiring re-operation (n=5) and death (n=5). Quality of life (QOL) was assessed to further understand challenges encountered after cardiac surgery in this resource-limited setting. Four major domains were considered: Health and Functioning, Social and Economic, Psychological/Spiritual, and Family. The mean total quality of life index was 20.79 ± 4.07 on a scale from 0-30, where higher scores indicated higher QOL. Women had significantly lower "Social and Economic" sub-scores (16.81 ± 4.17) than men (18.64 ± 4.10), (p < 0.05). Patients who reported receiving their follow-up care in rural health centers also had significantly lower "Social and Economic" sub-scores (15.67 ± 3.81) when compared to those receiving follow-up care in urban health facilities (18.28 ± 4.16), (p < 0.005). Value afforded to family as well as psychological factors remained high among all groups. Major post-surgical challenges faced included barriers to follow-up and systemic anticoagulation.

**Conclusions:** This report represents the first account of a long-term humanitarian effort to develop sustainability in cardiac surgery in a resource-limited setting. Utilizing volunteer teams to deliver care, transfer knowledge, and mentor local personnel, the results demonstrate superior outcomes and favorable indices of quality of life. The credibility gained over a decade of effort has created the opportunity for a serious partnership with Rwanda to establish a dedicated center of cardiac care to assist in mitigating the burden of cardiovascular disease in Rwanda and sub-Saharan Africa.
Cardiovascular disease in low and middle-income countries

Disproportionately affecting low and middle-income countries and chiefly regions of pervasive poverty, cardiovascular disease is responsible for more than one third of all deaths world-wide\(^1\). This disparity translates to an excess of three quarters of deaths occurring in low and middle-income countries. The consequential burden is directly related to the paucity of integrated primary health care programs designed to facilitate early detection and treatment of individuals with risk factors in these regions. The result is a surge in late detection or delayed diagnosis that leads to premature death from cardiovascular disease during the most productive years of life\(^1,2\).

Of the constellation of cardiovascular disease variants that saturate these areas, rheumatic heart disease (RHD) predominates as the leading cause of death responsible for a yearly mortality of over one million untimely deaths\(^2\). RHD is, therefore, the most common acquired cardiovascular disease among children and adolescents in sub-Saharan Africa, and it steadily confers severe disability in this region despite its near eradication in high-income countries.\(^3\) In fact, the prevalence of RHD in sub-Saharan Africa among children aged 5-14 years is 5.7 per 1000, while in developed countries it is only 0.5 per 1000.\(^4\)

With 1 physician per 10,500 individuals—including only 4 cardiologists in the public sector for a population of 11.4 million people, Rwanda represents a resource-limited setting that lacks the local capital to prevent, detect, and treat early cases of RHD. As a result, RHD in this region often advances unchecked toward requisite surgical intervention. However, surgery has not been possible, in the vast majority of instances, due to socioeconomic and health systems barriers\(^5,6,7\). Of equal importance, cost of medical management of end-stage RHD requires enormous investment, leading to personal or family debt\(^6,7\). Yet, the option of local partnership with humanitarian surgical outreach may represent a tenable solution to improving the delivery of cardiovascular care to resource-limited settings through mentorship, medical expertise, training, knowledge transfer and, ultimately, delivery of sustainable and safe cardiovascular surgery.

Quality of life following cardiovascular surgery in resource limited setting
Undeniably, cardiac surgery is a complex specialty that requires a robust infrastructure and the skills of a multidisciplinary team. For these reasons, access to this type of care has inherently remained restricted in resource limited settings. In fact, with the exclusion of South Africa, the ratio of cardiac surgery centers per million of inhabitants in sub-Saharan Africa is 1:33 (when excluding South Africa)—a striking global health disparity⁸. Within this context, it becomes apparent why millions of young patients worldwide with rheumatic or congenital heart disease are declined treatment or are unable to receive life sustaining operations each year⁴.

Given this set of circumstances, with a large population of people with advanced RHD needing surgery, in these settings, the vast majority of cardiovascular surgical procedures are provided through the efforts of humanitarian teams. Often these efforts focus exclusively on performing surgical procedures and do not engage in attempts to train local providers, transfer knowledge and engender progress toward sustainability. These programs undoubtedly are of benefit to the patients upon whom they perform surgery but leave little lasting impression on the health care capabilities of the host country. Other programs have a broader focus for their humanitarian efforts, including strategies which address disease screening/detection and prevention. These organizations also strive to employ care delivery strategies designed to improve standards of medical practice (e.g. proper use and monitoring of oral anti-coagulants), and to promote elements of sustainability. To date, there exist accounts of successful and failed attempts to provide sophisticated cardiovascular care, including cardiac surgery, to under-developed regions—like Rwanda⁹,¹⁰. However, no literature yet has investigated the post-operative quality of life among RHD patients in a resource-limited setting, a critical step in assessing the value of valve replacement and/or repair surgery in such settings. Quality of life may be impacted by such factors as patient gender, patient age, degree of social support, the location of the patient’s primary health center for follow-up care, or the type of valve replacement used – mechanical valves last longer than bioprosthetic valves but require lifelong anticoagulation therapy while bioprosthetics are prone to early degeneration in young patients but do not require lifelong anticoagulation. Though Rwanda is progressing toward decentralized health delivery with improved access to rural district hospitals, many patients must travel hours to receive routine post-operative, follow-up care. Some patients report bus trips of
up to 6 hours, while others describe walking 5-10 km to reach a clinic. The impact of this distance on both post-operative quality of life and adherence to the recommended plan of care may be even greater among patients with mechanical valves, who require more frequent follow-up appointments to monitor their anticoagulation therapy closely.

Now ten years after executing a program to provide cardiac surgery in Rwanda, we also summarize surgical outcomes for the organization to date. What we have learned provides a lens through which to examine the feasibility and efficacy of performing cardiac surgery in a resource-limited setting.

Team Heart

The Rwandan Genocide of 1994 destroyed much of the country’s health care capacity. When the health care system began to be rebuilt in the early 2000’s, a high incidence of heart failure was identified in hospitalized patients. This was due primarily to rheumatic heart disease (RHD). Team Heart was formed in 2006, in response to a request to address this problem of RHD with corrective heart surgery. The goal of Team Heart is to provide high-quality humanitarian cardiac care to Rwandans. From its inception, the vision of Team Heart has included not only addressing RHD with surgery, but engaging in disease screening and prevention and patient education; all the while focusing on information and skill transfer with the ultimate goal of establishing sustainable cardiac care in Rwanda. Team Heart has worked closely with the Rwandan Ministry of Health and the Rwanda Heart Foundation to organize annual surgical trips, to provide country-wide post-operative and anti-coagulation monitoring and nursing care, and to develop plans for a cardiac care center to be built in the capital city of Kigali. Team Heart is structured as a 501-C3 non-profit organization in the US, and is also a registered independent non-governmental organization (iNGO) in Rwanda.

METHODS

Logistics
Each year, the team is composed of 45-50 medical and non-medical volunteers. This group includes surgeons, cardiologists, intensivists, anesthetists, ICU and Stepdown nurses, pharmacist(s), perfusionists, biomedical engineer(s), trainees in general and thoracic surgery, cardiac anesthesia, cardiology, and non-medical volunteers who perform myriad duties both in and out of the hospital. A typical team composition for a recent trip is shown in Table 1. In the first few years, participants were predominantly recruited from Brigham and Women’s and Massachusetts General Hospitals. Currently, however, the team has members from 11 different states and 17 hospitals from all around the US and Canada. There are ten members who have travelled with the team each year from the inception of the project.

Funding

Team Heart has received grants from Edwards, St. Jude, Inc., and Medtronic, Inc. Furthermore, for each of the last three years, Team Heart has been awarded the ‘Every Heartbeat Matters’ Award from Edwards for the support of various aspects of this work. This effort is also supported by an ongoing philanthropic effort which is organized and managed by the Executive Director of Team Heart. All team members take vacation time and pay for their own travel. The Ministry of Health of Rwanda underwrites lodging for a portion of the team volunteers for the duration of the trip.

Equipment and Supplies

Much of the essential equipment has been generously donated to Team Heart. For example, heart-lung machines have been donated from US-based hospitals affiliated with members of the surgical team, reconditioned, and shipped to Rwanda. Additionally, serviceable hemodynamic monitors were donated to the team in 2006. These are currently in use in the operating theatre and the ICU in King Faisal Hospital—the hospital which hosts the visiting team.

Heart valves and annuloplasty rings have been very generously donated as gifts-in-kind by St. Jude Medical, Inc, Edwards, Inc, Sorin, Inc., and OnX, Inc. Each year, approximately 3000 lbs of supplies consisting of perfusion packs, suture material, thoracic drainage catheters, dressings, iv tubing, iv fluids, anesthesia supplies, etc., etc., etc. are
purchased or donated as gifts-in-kind; gathered in a storage facility outside Boston, meticulously labeled and packed to meet Rwandan Customs requirements, and air-freighted to Kigali. All supplies must have expiration dates at least 6 months after their projected arrival in Rwanda in order to ensure that out of date supplies will not be used during the visit. All necessary medications accompany the team. These are either purchased from, or, as in 2017, generously donated by the hospital pharmacy of the lead surgeon.

**Patient Selection**

A team consisting of two cardiologists and two cardiac sonographers, assisted by nurses, residents and students, arrive in the country approximately ten days prior to the arrival of the surgical team and the start of surgery. This team visits 3-4 sites distributed around the country and screens 75-100 potential candidates for surgery who have been referred to a local cardiologist. The majority of these candidates are among the most socioeconomically disadvantaged—and therefore the most vulnerable—who often have advanced disease due to lack of access to appropriate care. The data from this screening is carefully compiled, and, on the day prior to the beginning of surgery, the entire team, including the local team, meets for the purpose of establishing an operative list. A total of 16 cases are completed over the course of eight days (two cases per day). Given the disproportionate number of potential surgical candidates to the number of cases that can be performed, the selection process is both challenging and anguishing. The team is often left with the knowledge that some of the patients not selected will likely not survive until Team Heart or another expatriate team returns. Given the serious nature of these decisions, the process is inclusive, and all opinions are considered.

**Surgical Procedures**

All surgeries are performed through midline sternotomy incisions. Patients receive aortic and bi-caval venous cannulation for cardiopulmonary bypass. The lower weight limit accepted for surgery is 30 kg, given the limitations of the cannulae and other equipment available. Cardioplegic arrest is achieved with blood cardioplegia administered via both antegrade and retrograde routes. Intra-operative trans-esophageal echocardiography (TEE) is routinely employed to aid decision making and to facilitate post-operative procedural
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assessment. Valve replacement technique follows established practice, with Teflon felt re-enforced sutures routinely employed. Sutures are placed in non-evert ing fashion for aortic, and in either evert ing or non-evert ing fashion for mitral replacement, at the surgeon’s discretion. Repairs have been most frequently applicable for the tricuspid valve and have involved ring annuloplasty with either a Cosgrove or an MC3 ring (Edwards, Incorp.). Blood and blood products are very precious commodities in Rwanda. Meticulous attention is paid to the establishment of hemostasis at the end of each procedure. Returns to the Operating Theatre for bleeding are to be avoided, if at all possible.

Quality of Life Evaluation and Study Population

In addition to providing cardiac surgery for adolescents and young adults with critical valvular disease, we aimed to quantify the quality of life (QOL) of patients who have undergone open heart surgery in Rwanda and identify the impact of lifelong anticoagulation therapy on patient self-reported QOL. Additionally, we sought to investigate the geographical determinants of post-operative QOL: distance of patient residence to health clinic, and whether the primary site of healthcare was rural or urban.

The Ferrans and Power Quality of Life Index (QLI)-Cardiac Version was administered to 114 patients (63 female, 46 male, 5 unspecified) who had undergone cardiac surgery through Team Heart for treatment of RHD. The surveys divided the domains into four subcategories – Health and Functioning, Social and Economic, Psychological/Spiritual, and Family – along with calculating a total QOL score for each patient. A Rwandan nurse affiliated with Team Heart administered each survey on an individual basis (both in English and Kinyarwanda) to provide any necessary assistance with translation or literacy. All surgeries were performed between 2006 and 2014, so patients surveyed represented a variety of post-operative time periods. These patients came from villages, towns, and cities all over Rwanda, representing at least 25 of the 30 districts.

An additional survey regarding INR follow-up care was administered to those patients who received at least one mechanical valve (n=58). This survey, developed by Team Heart and administered by the same Rwandan nurse who administered the Ferrans and Power survey, focused on whether each patient’s INR values typically fell within, above, or below range, and how this was corrected for. The survey also questioned patients
regarding how far they had to travel to reach the location of their INR check appointments, and what barriers or obstacles they faced, if any, in regularly attending those appointments.

Statistical Methods

Student T-tests were performed between QOLs (overall and each subcategory) for females and males, and for patients who received care at urban vs. rural health centers. Qualitative variables were summarized as proportions and continuous variables with means and standard deviation. Bi-variate regression analysis was done using Odds Ratios, 95% confidence intervals and chi-square test was used to test for association of risk factors and variables. Statistical tests to assess the validity of association were Chi-square test (χ2) for subgroups. The significance of association was determined by calculations of P value and confidence interval. The two-sided p value <0.05 was considered confirming statistically significant association. A pretested, pre-coded and general questionnaire was used and crosschecked by the Principal Investigator to ensure completeness and validity before leaving the study site.

Ethical and Scientific approval was sought from the Institutional Review Board (IRB) at Brigham and Women’s Hospital in Boston, Massachusetts and King Faisal Hospital in Kigali, Rwanda. Informed written consent was sought from the caretakers of the study participants. The written assent was sought from the children aged 10 years and more.

RESULTS

Surgical Outcomes

Over ten trips, 149 procedures were performed, representing 200 valve replacements, 12 mitral valve repairs and 20 tricuspid valve repairs. Of those patients who underwent valve replacement, 175 received mechanical valves and 25 received bioprosthetic valves. Men represented 45.7% of the patient population, and average patient
age was 25.09 years (range 11-45 years). Early mortality, classified as mortality within 30 days of surgery, was 4.23%. Overall mortality from all causes was 8.4% (Table 2).

Student T-tests for Post-operative Quality of Life

Overall QOL scores showed no statistically significant difference between males and females, nor between patients seeking care at urban vs. rural health centers (Map 1); however, Social and Economic QOL scores showed statistically significant differences between each of these groups. For the entire patient population, the mean total Quality of Life Index score (QLI) was 20.79 ± 4.07 on a scale from 0-30, where 30 represents the highest possible quality of life. Women had significantly lower “Social and Economic” sub-scores (16.81 ± 4.17) than men (18.64 ± 4.10), (p < 0.05, Figure 1). Patients who reported receiving their follow-up care in rural health centers also had significantly lower “Social and Economic” sub-scores (15.67 ± 3.81) when compared to patients receiving their follow-up care in urban health facilities (18.28 ± 4.16), (p < 0.005, Figure 2).

DISCUSSION

In austere settings, understanding of the true burden of RHD is limited to estimates, many of which are thought to be under-representative. To date, most studies refer to World Health Organization (WHO) reports, which suggest that approximately 15.6 million individuals worldwide are afflicted with RHD. Approximately 282,000 new cases and 233,000 deaths are being recorded annually. Additionally, another 188,000 cases of acute RF are estimated to develop each year. These cases exist within a milieu of approximately 727 million new cases of group A β-hemolytic streptococcus infection annually, creating a major public health problem in the developing world. Furthermore, there are 2.4 million affected children between 5 and 14 years of age in developing countries, 1 million of whom live in sub-Saharan Africa, making the region a major RF/RHD hotspot.

In November 2006, the Government of Rwanda began an effort to decentralize chronic care for non-communicable conditions, including cardiovascular diseases. In line with this national target, the Rwanda Ministry of Health sought to develop sustainable programs to fight common cardiovascular conditions, with the help of national and
international experts. Thereafter, a collaborative effort was initiated between the Rwanda Ministry of Health, King Faisal Hospital, Kigali, four expatriate surgical visiting teams and the Rwanda Heart Foundation, to determine the scope of cardiac disease in the country and to coordinate treatment efforts, including screening, prevention, prophylaxis, and surgical interventions for those with congenital and advanced acquired cardiac disease.

Steps toward a comprehensive cardiac surgery program in Rwanda
The goal of Team Heart is to facilitate a partnership with the Rwanda Ministry of Health to establish a sustainable, independent, dedicated cardiac care center for children and adults with all forms of heart disease, which would be a center of excellence in the country and for all of East Africa. Of necessity, the Center would initially be staffed largely by expatriate physicians and nurses, while their Rwandan counterparts are being trained. Over time, it is anticipated that the staff will transition to primarily Rwandan nationals. Clearly, one such center is not adequate for the entirety of the Rwanda population. However, when operating at full capacity, it will become the major focus of clinical care, education and research for cardiovascular disease for Rwanda and the region. This success will foster replication in the region over time. The partnership will strengthen surgical options available in Kigali, Rwanda on three levels by: expanding local capacity for cardiac surgery, reinforcing registry-based secondary prophylaxis, and enhancing treatment of streptococcal infections. Currently, TH functions within the existing health care infrastructure of Rwanda, but with its own financing, management and staff organizations. The scaling up which this vision entails, however, cannot occur based on humanitarian and philanthropic efforts alone. To address this issue, parallel efforts are ongoing to engage the Rwandan government in a plan to incorporate funding for cardiovascular care in the national healthcare planning paradigm. The goal is for cardiovascular care to become a self-sustaining module of the Rwandan health care system, interdependent upon the primary care and prevention modules already in place and arising throughout the country.

Training of Critical Providers
An important piece of this transition is the shift in responsibility of the medical/surgical staff, which will occur through continued education of the local health
care workforce. The most time-consuming hurdle on the path toward sustainability is the identification and training of a local cardiac surgeon. Accordingly, efforts were made early in TH’s presence in Rwanda to identify such an individual and to explore the routes available for him/her to be trained properly. Such an individual has been identified, and TH is now working closely with the Rwandan Ministry of Health in supporting the mentorship of this resident as he pursues his training in general and cardiothoracic surgery at the University of Witwatersrand in South Africa. While he completes his training, other key personnel are being identified and trained.

In-country education and skill transfer

In addition to facilitating distant training, in-country surgical education and skill transfer have been important components of the TH model. During initial visits, the staff cardiothoracic surgeon was first assistant for portions of procedures and observed many others. Multiple medical students and residents from the medical school at the National University of Rwanda and from KFH observed each case. Conscious mentoring by TH surgeons served to increase interest in the field cardiac surgery and awareness of the need for the intervention within Rwanda. Also, cardiac anesthesiologists from TH have worked closely with local Rwandan anesthesiologists and anesthesia trainees during its surgical trips to provide education in intra-operative and postoperative anesthetic care. The team has also utilized intraoperative transesophageal and pre- and post-operative transthoracic echocardiography as teaching tools for discussing patient selection, operative procedures and post-operative care. Nursing education has occurred at both the bedside and through the sharing of resources. Seminars have been facilitated with KFH nursing leadership to provide education on diagnosis and care, from pre-operative through post-operative, in a variety of settings. Team Heart further continues to be committed to working with supporting nursing education at both the Baccalaureate and Masters levels in partnership with the Kigali Health Institute and the Biomedical Research Center. Additionally, in 2009, an individual was identified with interest in cardiac perfusion. A training program in India was located, and that candidate completed the training curriculum. Afterwards, this gentleman has worked closely with TH during its subsequent trips to assist in providing cardiac perfusion during cases. As education of the local team continues, TH hopes to
remain involved in the role of mentorship. Over time, the group plans to gradually increase the responsibility of the Rwandan team, expecting them to demonstrate their competency with increasingly complicated procedures.

*Robust screening and prevention programs*

Another step towards managing the burden of RHD in Rwanda is delineating its true burden and the extent of the disease. In 2011, Team Heart carried out the first echocardiographic prevalence survey in the Gasabo district of the country (which includes Kigali) to help raise awareness of the problem of RHD and to identify the age groups most affected. In addition to attempting to determine the prevalence of RHD in a sample of Rwandan school children using the 2012 World Heart Federation (WHF) echocardiographic criteria, the purpose of this study was to identify those individuals who have not yet progressed to acute rheumatic heart disease but could benefit from earlier intervention\textsuperscript{11,12}. The findings of this study demonstrated an RHD prevalence of 6.8/1 000 children examined (95% CI: 4.2/1 000–10.9/1 000). This indicates a significant burden of RHD in Rwanda and supports a need for defined public health programs to control Strep Throat and Acute RF in children. Secondarily, it revealed the need to work with partners to identify and overcome barriers to primary care that typically hinder children and young adults from seeking treatment for the sore throats and skin infections that may precipitate rheumatic fever. Such research not only helps define the size of local problems, but it also aids in the evolution of effective approaches to develop and implement these initiatives: a comprehensive school health program and the requisite public policy for improving it, an educational curriculum for healthcare workers and the public, an echocardiographic screening program, a registry of identified RHD cases, a program to identify the strains and serotypes of group A streptococci involved in rheumatic fever and RHD in Rwanda, a program for early treatment of group A streptococcal infections among school-aged children, and a promotion of secondary prophylaxis of RHD\textsuperscript{13, 14, 15, 16}.

**Conclusion**
This study assessed the outcomes of rheumatic heart disease surgery in Rwandan adolescents and young adults and found that the surgery is associated with good clinical outcomes. There is much improvement of heart function and gratifying clinical recovery of patients, with achievable improvement in quality life. However, these patients need thorough clinical and psychosocial follow-up. This report represents the first account of a long-term humanitarian effort to develop sustainability in cardiothoracic surgery in a resource-limited setting with superior outcomes; utilizing volunteer teams to deliver care, transfer knowledge, mentor local personnel and train key individuals to assist in mitigating the burden of cardiovascular disease in sub-Saharan Africa. Moving forward, preventive measures of acute rheumatic fever and rheumatic heart disease should be among health prevention program priorities. TH has laid the foundation for a comprehensive program that could eventually absolve the country of the disease. However, it is ultimately the responsibility of the Rwandan government and stakeholders in its health system, which will have to guide the focus toward scientifically addressing the problems related to prevalence, incidence and distribution of disease.

Finally, through a decade of dedicated effort and demonstrated success, a platform has been created which can be leveraged for the creation of the desperately-needed next level of care for this neglected part of the world, namely a dedicated cardiac care center for Rwanda and the region.

References