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

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Scholarly Report submitted in partial fulfillment of the MD Degree at Harvard Medical School

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Scholarly Report Title: Ten Year Clinical Experience of Humanitarian Cardiothoracic Surgery in Rwanda: Building a Platform for Ultimate Sustainability in a Resource-Limited Setting

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Abstract

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


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 4 cardiologists for a population of 11.4 million, Rwanda represents a resource-limited setting lacking the local capacity 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 Powers Quality of Life Index (QLI) tool’s 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 4.7% 30-day mortality. All procedures were performed with participation of local Rwandan personnel, alongside expatriate physicians, nurses, residents and support staff. Early complications included CVA (n=4), hemorrhage requiring re-operation (n=6) and death (n=7). 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" subscores (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 postsurgical 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 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.
Scholarly Report

Student Intellectual Contribution

I first became involved with Team Heart in the fall of 2014, when I started learning about the organization and working with collaborators Ceeya Patton-Bolman, Dr. R. Morton Bolman, and Dr. JaBaris Swain. As Team Heart prepared for another annual surgical trip in February 2014, the organization was also beginning to develop plans for a dedicated cardiac center in Rwanda. My intended role was to collect and analyze data on the costs associated with cardiac surgery in Rwanda to better inform a cost-effectiveness analysis that would assist in this planning.

I traveled to Kigali, Rwanda in July 2015, where I had extensive informative conversations with Rwandan cardiologists and cardiac nurses. The time I spent there provided a crucial lens of the scope and importance of the project. Though I initially traveled to Rwanda with the goal of collecting cost data, I unfortunately encountered significant obstacles to collecting this data. After meeting with several officials in the Ministry of Health, I was informed that I would not be allowed to collected data specific to surgical costs and materials. Therefore, upon my return to the United States, I switched the focus of my project from investigating the cost side of a cost-effective analysis to a achieving a deeper understanding of the value gained from cardiac surgery in Rwanda. Team Heart had already collected well over 100 surveys from post-operative patients that included demographic information and a standardized quality-of-life assessment tool. Over the ensuing weeks, I created a complete database of all information contained in the surveys. Using this database, I performed statistical analysis using SPSS to evaluate variation in post-operative quality of life among different patient sub-populations.

One of the products of this analysis was a comprehensive geographical map of the country of Rwanda including data points for each patient coded by the location of the health center at which they received follow-up care. This map enabled the team to visualize the incredible distance some patients chose to travel in order to receive care at an urban academic rather than at a rural community center, a realization that then spurred further analysis of how geographical distance from a patient’s follow-up healthcare center may negatively impact self-reported quality-of-life. This was especially relevant as Team Heart considered how to structure
future post-operative care in Rwanda, as patient’s frequently receive mechanical valves necessitating anticoagulation and close follow-up for optimal post-operative management.

After I presented my preliminary findings on the effects of patient gender and rural vs. urban location on self-reported post-operative quality of life at the Harvard Medical School Soma Weiss Research Day, this analysis was subsequently further explored in greater detail and ultimately featured prominently in an oral presentation that Team Heart co-founder, Dr. Bolman, gave during the Plenary Session of the Centennial Conference for the American Association of Thoracic Surgery (2017). During the presentation, he detailed the outcomes, and obstacles, that Team Heart had observed since its inception ten years ago. I contributed slides to this presentation, as well as to a presentation given by Dr. Swain at the Brigham and Women’s Hospital Surgical Grand Rounds (2017). The slides that I contributed including original tables and figures that I had created, featuring my post-operative patient quality of life analyses by demographic sub-groups and the detailed map I had generated with patient follow-up care locations.

In the late summer and fall of 2017, Dr. Swain and I prepared and submitted a manuscript detailing our project, including my work on post-operative self-reported quality-of-life. I was a contributing or solo author on the following sections of this manuscript: Background; Methods: Quality of Life Evaluation and Study Population; Methods: Statistical Methods; Results: Student T-tests for Postoperative Quality of Life; and Discussion. I also designed all figures related to post-operative quality of life that appear with the manuscript.

### Background and Rationale for Study

Cardiovascular disease causes 30% of all deaths worldwide but disproportionately affects low and middle-income countries, which bear 80% of the world’s burden of cardiovascular disease.\(^1\) Worldwide, rheumatic heart disease (RHD) causes over one million premature deaths each year.\(^2\) Despite its near eradication in high-income countries, RHD is the most common acquired cardiovascular disease among children and adolescents in sub-Saharan Africa and continues to cause severe disability in both children and surviving adults.\(^3\) 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.\(^4\) In resource-poor settings like Rwanda, it is difficult to maintain consistent preventive care for RHD and the disease often advances to a stage where
patients require surgical intervention, which historically has not been possible in most cases due to socioeconomic and health systems barriers.\textsuperscript{5}

Cardiac surgery poses enormous challenges in low-income countries like Rwanda. In Rwanda, a country of more than 12 million people, there are only 9 anesthetists and 17 surgeons.\textsuperscript{6} None of these surgeons are cardiac surgeons, and in the Rwandan public sector, there are only four cardiologists.\textsuperscript{7} Through organizations like Team Heart, international humanitarian surgical teams provide the only cardiac surgeries in the country. Besides these logistical barriers to surgery, the financial burden of cardiac surgery is a major limiting factor. Costs of end-stage treatment for RHD in resource-poor settings require enormous investment, often leading to personal or family debt. Additionally, opportunity costs associated with the lost productivity of RHD patients, who are typically young and would otherwise be working or contributing to household maintenance, are high.

Recent research has identified life-saving or disability-preventing surgeries as cost-effective interventions in low-income countries, despite common misconceptions that surgery is too expensive or complex for incorporation into the global health sphere.\textsuperscript{8,9} A systematic review of various surgical procedures performed in low-income countries found that cataract surgery cost $5.06-$106.00 per DALY averted; highly active anti-retroviral therapy for HIV, on the other hand, cost $922.00 per DALY averted.\textsuperscript{8} Caesarean sections, which cost $315.12 per DALY averted, are more cost-effective than HIV treatment with multidrug anti-retroviral therapy, which in another analysis cost $453.74-648.20 per DALY averted.\textsuperscript{9}

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, 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 bioprostheses do not. In a setting in which simply achieving a single valve replacement surgery for a patient is incredibly challenging, reoperation to replace a bioprosthetic valve is almost never an option. (Exceptions to this rule are almost exclusively among women of reproductive age in whom anticoagulation with warfarin is strictly contraindicated.) Though Rwanda is currently working towards a more decentralized healthcare system with improved access to healthcare in rural districts, many Team Heart patients still face
journeys of many hours or more for routine follow-up care post-operatively. Some patients reported bus trips of up to 6 hours, while others described walking 5 km to reach a clinic. The impact of this distance on post-operative quality of life may be even greater amongst patients with mechanical valves, who require more frequent follow-up appointments to monitor their anticoagulation therapy closely.

Understanding cardiac patients’ self-reported post-operative quality of life would help to provide a context of the value of cardiac surgery for treatment of RHD in Rwanda, a country seeking to improve access to healthcare via simultaneous integration and decentralization of care. Additionally, as Rwanda continues to plan the construction of a new cardiac health facility and bolster surgical capacity, a study of cardiac patient quality of life after surgery would help to lay the groundwork for future studies in cost-effectiveness, contribute to the effective implementation of a domestic cardiac surgical program, and direct planning of optimal post-operative patient care.

We aimed to quantify the quality of life (QOL) of Team Heart cardiac patients post-operatively, especially investigating 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.

Impact

The Journal of Thoracic and Cardiovascular Surgery accepted a paper detailing our results for publication in November 2017; however, it has not yet been published as the journal editors have decided to publish it along with invited commentary. As the paper has not been published as of the date of my submission of this report, a recent draft has been provided in Appendix 1. Upon publication of the paper, which per the journal editors should be imminent, I will provide a link to the publication along with its citation. Clearly, as evidenced by the invitation for this research to be presented during the Plenary Session of a Centennial Conference and by the editors’ decision to publish this manuscript with academic invited commentary, our project contributes novel findings on the successful potential for surgical management of disease in resource-limited settings.

By initiating a discussion among the international cardiothoracic surgery community
focused on provision of cardiac surgery in resource-limited settings, we are hopeful that Team Heart’s work will encourage other surgeons to pursue similar work. Additionally, as Team Heart continues to work closely with their Rwandan colleagues to develop and construct a dedicated cardiac center in Kigali, my work focused on the impact of geographic distance from follow-up health care centers will help to inform how post-operative care delivery may be structured in Rwanda moving forward. It is our hope that this model could then be replicated in other resource-limited settings.
References

Appendix 1

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

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Glossary of Terms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>RHD</td>
<td>Rheumatic heart disease</td>
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<tr>
<td>QLI</td>
<td>Quality of life index</td>
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<tr>
<td>NYHA</td>
<td>New York Heart Association</td>
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<tr>
<td>CVA</td>
<td>Cerebrovascular accident</td>
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<tr>
<td>QOL</td>
<td>Quality of life</td>
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<td>TEE</td>
<td>Transesophageal echocardiography</td>
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Figure Legend [Video]

Video: Team Heart is a non-profit organization that aims to address and prevent rheumatic heart disease in Rwanda. Team Heart's history and mission is explained, with visual story telling of their journey.
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 4 cardiologists for a population of 11.4 million, Rwanda represents a resource-limited setting lacking the local capacity 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.

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**Results:** Ten visits have been completed, performing 149 open procedures—including 200 valve implantations [NYHA class III or IV] with 4.7% 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=4), hemorrhage requiring re-operation (n=6) and death (n=7). 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 postsurgical 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 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.

**BACKGROUND**

*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 worldwide\(^1\). In excess of three quarters of these deaths occur 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 early adulthood, the most economically productive years of life\textsuperscript{1,2}.

Of the constellation of cardiovascular disease variants that saturate these areas, rheumatic heart disease (RHD) is responsible for a yearly world-wide toll of over one million untimely deaths\textsuperscript{2}. RHD is 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\textsuperscript{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\textsuperscript{4}.

Rwanda is a small, mountainous East African country with a population of nearly 12 million people. The capital city is Kigali, which is located in the center of the country, and contains the only hospital in Rwanda capable of hosting a visiting cardiac surgery team-King Faisal Hospital. King Faisal was built with Saudi funding in the 1960’s and was the site of killing of many doctors and nurses during the genocide. Now, 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 capacity to detect, prevent, and treat early cases of RHD. As a result, RHD in this region often advances unchecked toward advanced stages, requiring surgical intervention. However, surgery has not been possible, in the vast majority of instances, due to socioeconomic and health systems barriers\textsuperscript{5, 6, 7}. Of equal importance, cost of medical management of end-stage RHD requires enormous investment, leading to personal or family debt\textsuperscript{6, 7}. In this desperately resource-limited circumstance, the option of local partnership with humanitarian surgical outreach may represent a tenable solution
to improving the delivery of cardiovascular care. This can occur through mentorship, medical expertise, training, knowledge transfer and, ultimately, delivery of sustainable and safe cardiovascular surgery.

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 remained largely unavailable in resource-limited settings. In fact, with the exclusion of South Africa, the availability of cardiac surgery centers per million of inhabitants in sub-Saharan Africa is 1 program for every 33 million people. By comparison, in the US the ratio is 1 program for every 120 thousand people. By any measure, this represents a striking global health disparity. These data explain why millions of young patients world-wide with rheumatic or congenital heart disease are declined treatment or are unable to receive life-sustaining operations each year.

Given this set of challenges, the vast majority of open cardiac procedures are provided through the efforts of humanitarian teams. At times, efforts focus exclusively on performing surgical procedures and do not engage in attempts to train local providers, transfer knowledge, ensure follow-up care, and engender progress toward sustainability. These programs undoubtedly are of benefit to the patients who undergo surgery but leave little lasting impression on the health care capabilities of the host country. Other programs have a broader focus, 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 anticoagulants), and to promote elements of sustainability.

Quality of life following cardiac surgery in resource-limited setting

To date, there exist accounts of successful and failed attempts to provide sophisticated
cardiovascular care, including cardiac surgery, to under-developed regions—like Rwanda\textsuperscript{9, 10}. However, no literature has yet investigated the postoperative quality of life among RHD patients in a resource-limited setting, a critical step in assessing the value of valve replacement and/or repair 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 bio-prosthetic valves but require lifelong anticoagulation therapy while bio-prostheses 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 postoperative, follow-up care. Some patients report bus trips of up to 6 hours, while others describe walking many kilometers to reach a clinic. The impact of this distance on both postoperative 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 implementing a program to provide cardiac surgery in Rwanda, we summarize surgical outcomes to date. We also quantify the quality of life (QOL) of patients who have undergone open heart surgery in Rwanda and identify the impact of life-long anticoagulation therapy on patient, self-reported QOL. Additionally, we investigate the geographical determinants of postoperative QOL through the metric of whether the primary site of health care was rural or urban.

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 saw nearly a million people killed in 100 days of unspeakable violence of one tribe against another. This tragedy also played out in possibly an even more devastating manner, in that it destroyed much of the country’s health care capacity. When rebuilding of the health care system began in the early 2000’s, a high incidence of heart failure was identified in hospitalized patients. This was discovered to be due primarily to rheumatic heart disease (RHD). Team Heart was formed in 2006, in response to a request from the Minister of Health to address the burden of RHD with corrective heart surgery. The goal of Team Heart is to provide high-quality humanitarian cardiac care to Rwandans. Since its inception, Team Heart’s vision has included not only addressing RHD with surgery, but also 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 postoperative and anticoagulation 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 (Table I).

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, including corporate volunteers, who perform myriad duties both in and out of the hospital. In the first few years, participants were predominantly recruited from Brigham and Women’s and Massachusetts General Hospitals. Currently, however, the most recent edition of the team has members from 5 different countries, 11 different states and 17 hospitals. There are ten members who have travelled with the team each year from the inception of the project.

Funding

Team Heart has received grants-in-aid 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 Lifesciences Foundation and the Thoracic Research Foundation 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, and iv infusion pumps, at end-of-service in the US, but perfectly serviceable, have been donated from US-based hospitals affiliated with members of the surgical team, reconditioned, and shipped to Rwanda by Team Heart. Additionally, serviceable hemodynamic monitors were donated to the team in 2006. These are currently in use in the
operating theatre and the intensive care unit in King Faisal Hospital—the hospital which hosts the visiting team.

Heart valves and annuloplasty rings have been generously donated as gifts-in-kind by St. Jude Medical, Inc, Edwards Lifesciences, LivaNova, and OnX, Inc. Cardiac surgical instruments have been generously donated by Scanlan International, Inc. Perfusion supplies have been donated by Medtronic, Inc. Each year, approximately 1500 pounds of supplies consisting of perfusion packs, suture material, thoracic drainage catheters, dressings, IV tubing, IV fluids, anesthesia supplies, etc. are purchased or donated as in-kind gifts; 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 outdated 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 group consisting of two cardiologists and two cardiac sonographers arrives in the country approximately ten days prior the surgical team and the start of surgery. This group, assisted by local and US nurses, residents and students, visits sites around the country and screens 75-100 potential candidates for surgery who have been referred by a local cardiologist. The majority of these candidates are among the most socioeconomically disadvantaged—and therefore, the most vulnerable —of Rwanda, 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 visiting and 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 bicaval 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. Intraoperative transesophageal echocardiography (TEE) is routinely employed to aid decision-making and to facilitate postoperative procedural assessment. Valve replacement technique follows established practice, with Teflon felt-reinforced sutures liberally employed. Sutures are placed in noneverting fashion for aortic valve replacement, and in either everting or noneverting fashion for mitral valve 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.). Early in the experience, in an attempt to avoid the necessity of anti-coagulation, mitral valve repairs were performed utilizing some of the techniques employed for degenerative mitral valve disease. This included leaflet extension with bovine pericardium for cases of leaflet restriction, as well as other techniques addressing the leaflets, supplemented by ring annuloplasty. These techniques were disappointing in terms of
durability. In a setting where reoperation is not currently possible, these techniques were abandoned. 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. The Ferrans and Powers 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 postoperative time periods. These patients came from villages, towns, and cities all over Rwanda, representing at least 25 of the 30 districts.

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. 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, precoded 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 the space of 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 4.7% (Table 2). Overall mortality from all causes was 9.4%.

Student T-tests for Postoperative 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. 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” subscores (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).

Responses to more global questions revealed that the patients had an encouraging level of community, professional and family engagement. 61.4% of patients said that they were moderately satisfied to very satisfied with “their ability to take care of their financial needs”, and 80.7% said they were moderately satisfied to very satisfied with “their ability to take care of family duties”. Given that these patients preoperatively were in advanced stages of RHD, and would likely be dead or in the last throes of their disease without surgery, this represents a striking and hopeful positive level of self-reporting.

DISCUSSION

In austere settings, understanding of the true burden of RHD is limited to estimates, many of which are thought to be underrepresentative. 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 rheumatic fever 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\textsuperscript{7, 8}. 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 RHD hotspot\textsuperscript{8, 9}.

In the report of a WHO Expert Consultation on “Rheumatic Fever and Rheumatic Heart Disease,” experts estimated that 770,000 disability-adjusted life years (DALYs) are lost to RHD in the African region, with a rate of roughly 119.8 per 100,000 of the population\textsuperscript{5}. Similarly, there are roughly 12,000 DALYs lost in Rwanda alone due to RHD. Considering that this number is for the entire continent of Africa, and that the WHO report on the burden of group A streptococcal disease lists the Middle East and North Africa as having a significantly lower prevalence rate of RHD in children 5-14 (1.8 per 1000 as compared with 5.7 per 1000)\textsuperscript{8}, it is highly likely that the loss of DALYs in Rwanda is even higher than this estimate, underscoring the critical nature of this important public health problem.

RHD patients who qualify for cardiac surgery in Rwanda are so sick as to be unable to work or perform household tasks, though they are of ages typically associated with some of the most economically productive years of life (average patient age range 22-28 years). This discrepancy further exacerbates the impact of RHD on DALYs in Rwanda. In the postoperative QOL surveys, though, Team Heart patients reported encouraging levels of community, professional, and household engagement. Of these patients, 61.4% reported that they were moderately satisfied or very satisfied with their ability to “take care of their financial needs,” and the overwhelming majority (80.7%) reported that they were moderately satisfied or very satisfied with their “ability to take care of family duties.” Among patients who, without surgery, would have been hospitalized or deceased, this level of self-reported productivity is striking.
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 patient care 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, Team Heart 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 Team Heart’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 Team Heart 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 Team Heart 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 King Faisal Hospital observed each case. Conscious mentoring by Team Heart surgeons served to increase interest in the field of cardiac surgery and awareness of the need for the intervention within Rwanda. Also, cardiac anesthesiologists from Team Heart have worked closely with local Rwandan anesthesiologists and anesthesia trainees during its surgical trips to provide education in intraoperative and postoperative anesthetic care. The team has also utilized intraoperative transesophageal and pre- and postoperative transthoracic echocardiography as teaching tools for discussing patient selection, operative procedures and postoperative care. Nursing education has occurred at both the bedside and through the sharing of resources.
Seminars have been facilitated with King Faisal Hospital nursing leadership to provide education on diagnosis and care, from preoperative through postoperative, 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 Team Heart during its subsequent trips to assist in providing cardiac perfusion during cases. As education of the local team continues, Team Heart will 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. 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 rheumatic fever 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

Challenges to providing cardiovascular care in a resource-limited setting

Rwanda is classified as a “third-world” entity; however, the country has made, and continues to make tremendous strides towards economic recovery and growth that has surpassed the development of many other countries with this designation. That said, specific surgical issues within the Team Heart experience were many, presenting real challenges to providing complex cardiovascular care for patients within this resource-limited setting.

First and foremost, the restricted duration of each Team Heart visit and the available human resources could only accommodate a minimum expatriate team to partner with Rwandan personnel. Each ensuing year has presented the charge to make the volunteer team smaller and smaller to promote sustainability while optimizing the learning opportunity and participation among the local care providers. There is the general need to have enough expatriate providers to
carry out the daunting task of the operative component of the trip as well as shepherd the postoperative care. However, there remains a balancing act of attempting not to be overbearing and to allow for inclusiveness among the native providers as well, such that skill transfer and teaching is prioritized.

Once a cohesive team is assembled, patient selection becomes the next critical challenge. This is the most difficult and daunting aspect of the trip each year. Many patients with severe disease are discovered through the Team Heart screening program, but constraints of time and resource availability only allow for care to be extended to those with the best chances of survival and overall improvement. Given these constraints, only 16 patients can be offered surgery each trip. Unfortunately, this leaves behind many critically ill, young patients who, in many cases, will not live to see the next year for the return trip.

Once patients are selected, size limitation is the next challenge. Many of the patients seen are quite small because of their chronic heart failure and as a sequela of failure to thrive. However, the team employs a lower weight limit of 30 kg, which in many ways stretches the margins of our perfusion equipment. In general, patients tend to have very small aortas, apart from those with aortic valve disease. This anatomical feature poses some challenges with respect to safe cannulation. Atria are quite large, so AV valve exposure is generally good. The chest sizes are small relative to the enlarged heart size. Overall, extreme technical agility is critical for cannulation and transitioning these patients on and off cardiopulmonary bypass without causing untoward harm.

Availability of blood was a serious problem in the first 6-7 years. Blood was kept off site, and was at least an hour away. Take-backs were to be avoided at all costs. In the last 3-4 years, however, there has been present the ability to request platelets, FFP, and cryoprecipitate.
Additionally, there is always 4 units of PRBC’s available for each patient. We do not offer re-operative heart procedures now, due to the enormous backlog of un-operated patients, and the fact that we have a limited number of operative openings in any given trip.

ICU care, in general, is superb, as Team Heart has provided dedicated ICU physicians and nurses who are intimately involved in the care of the patients alongside native providers. There is round-the-clock, immediate availability of TEE, cardiac anesthesia, surgery, pharmacy, and any other resources that are required. The team often comments that the resources available for care in the ICU were better than those in the US.

As to causes of death, the majority are noted to be anticoagulation-related deaths and the unfortunate propensity to use iv vit. K to reverse elevated INR’s, even in patients with mechanical valves, with subsequent valve thrombosis. Also, in terms of postoperative care problems, a principal one was difficulty with patients gaining access to care facilities for care after discharge due to distance from center and lack of resources, financial and otherwise. This eventuated in delayed diagnosis and treatment of heart failure in a significant number of patients. Precipitous heart failure and demise has, unfortunately, been the outcome in a select number of cases over the ten-year experience.

**Conclusion**

This study assessed the outcomes of surgical treatment of rheumatic heart disease 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 measurable improvement in quality of life. This report represents the first account of a long-term humanitarian effort to develop sustainability in cardiothoracic surgery in Rwanda with superior outcomes. We have demonstrated the effectiveness of 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\textsuperscript{15}. Moving forward, preventive measures of acute rheumatic fever and rheumatic heart disease should be among health prevention program priorities. Team Heart has laid the foundation for a comprehensive program that could eventually eliminate RHD from the country.

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


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