



# Delivery of Advanced Pediatric Surgical Care as a Model for Health Equity, Education, and Development: the First Separation of Conjoined Twins in Haiti

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## Abstract:

Equitable surgical care for children is an essential component of basic human rights, but has largely been forgotten among the priorities of global surgery. The delivery of pediatric surgical care is inadequate in many low- and middle-income countries (LMICs) due to lack of specialty trained providers, health care resources, and infrastructure. Building pediatric surgical capacity through multinational partnerships concentrating on education of local practitioners is essential for sustainable, self-sufficient delivery of healthcare. We discuss the successful multidisciplinary delivery of advanced pediatric surgical and critical care in Haiti during the separation of conjoined twins as an example of an effective partnership.

**Keywords:** Conjoined twins; Haiti; International pediatric surgery; Multidisciplinary; Global health; Critical care

## Introduction

### Pediatric surgical care as an essential component to the delivery of equitable health care

The right to healthcare has been recognized among the most basic of human rights since the Universal Declaration of Human Rights was ratified in 1949<sup>[1]</sup>. In 1966, this definition was expanded, declaring that all people have the "right to the highest attainable standard of health"<sup>[2]</sup> Surgical care and anesthesia were officially identified and prioritized at the multinational level as essential components of health investment and health system strengthening by the World Health Assembly in May 2015<sup>[3]</sup>. Essential surgical procedures rank among the most cost effective of any health intervention and avert at least 6-5 % of deaths in low- and middle-income countries (LMICs), further justifying their inclusion as part of a basic health care package that equitably addresses priority disease conditions<sup>[4]</sup>.

In accordance with the "right to the highest attainable standard of health" equitable delivery of surgical care should include both essential and advanced surgical care in the local context. In LMICs, this objective is hampered by a dearth of human resources, specialty training, equipment and infrastructure<sup>[5,6]</sup>. While many of these obstacles are

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difficult for LMICs to overcome independently, the Declaration of Alma Alta recognizes the power of multidisciplinary, international cooperation in order to achieve the highest attainable standard of health.

Pediatric surgery requires advanced specialty training and is essential to providing equitable delivery of surgical care and reducing infant and child mortality, especially in LMICs where nearly 40-50 % of the population is less than 21 years old<sup>[7,8]</sup>. Congenital anomalies and perinatal emergencies are among the most common pediatric pathologies with the former accounting for 25.3-38.8 million disability-adjusted life-years (DALYs) worldwide, as well as 10% of all neonatal deaths globally<sup>[9-11]</sup>. Furthermore, congenital anomalies may account for roughly 120 DALYs per 1,000 children<sup>[12]</sup>. Almost 95% of congenital anomalies occur in LMIC<sup>[10]</sup>. Surgery can reduce nearly 60 % of the burden of cost and care for the most prevalent anomalies if comparable outcomes are achieved in LMICs as they are in high-income countries<sup>[8,13]</sup>. Unfortunately, fewer surgical procedures are performed in LMICs compared to high-income countries, even though the former account for the greatest burden of surgical disease globally and the largest proportion of children<sup>[7,8]</sup>.

Advanced pediatric surgical care is not available in many LMICs due to a wide variety of factors. As a result, while survival for many neonatal conditions in high-income countries is 80-100 %, the mortality rate in LMICs approaches 80-100%, with mortality from neonatal surgery alone reported as high as 20-30 %<sup>[7]</sup>.

### **Pediatric surgical care in Haiti**

Haiti is the poorest country in the western hemisphere<sup>[14]</sup>. On January 12, 2010, a 7.0 Mw magnitude earthquake struck the capital, Port-au-Prince, inflicting significant damage to health facilities and hospitals, straining or incapacitating an already inadequate healthcare infrastructure. Eight years later, and compounded more recently by Hurricane Matthew, the delivery of advanced healthcare to the people of Haiti remains a challenge.

The population of Haiti is 10.4 million with over one third under 14 years of age<sup>[15,16]</sup>. The infant mortality rate in Haiti is 40.2/1,000 live births, almost 7 times higher than that of the United States.<sup>16</sup> There are 2.3 physicians per 10,000 people, compared to the LMIC average of 5.1 and a global average of 14.2<sup>[17]</sup>. The majority of physicians are located in the capital, creating a system of inequitable delivery of healthcare within the country. Many hospitals perform neonatal procedures, but often these are not done by specialty-trained pediatric surgeons and outcomes data are wanting<sup>[17]</sup>. The American Pediatric Surgical Association indicates that the need for pediatric surgeons is 1 per 100,000 children age 0-15 years<sup>[18]</sup>. However, there are only 2 full-time specialty trained pediatric surgeons in Haiti<sup>[15,16]</sup>.

Our team works with two hospitals in Haiti that regularly provide pediatric surgical care to the children of Port-au-Prince and the central plateau. Hospital Bernard Mevs - Project Medishare (HBM) is one of Haiti's few trauma, critical care, and rehabilitation hospitals located in the capital. Prior to 2010, HBM was a 10-bed community hospital and clinic. After the earthquake, Project Medishare joined HBM to improve and expand upon treatment of critically ill and injured Haitians. A primary goal of HBM is to train the next generation of Haitian

healthcare providers in order to build capacity and ultimately end the need for foreign medical assistance<sup>[19]</sup>. Despite having only 50-beds, HBM treats 60,000 patients annually, including 3,190 trauma patients. Inpatient pediatric care is provided in a 10-bed pediatric ward, a 4-bed pediatric intensive care unit (ICU), and a 4-bed neonatal ICU. While HBM is located in Port-au-Prince, it often treats patients who have traveled for hours from across the country to receive medical care, highlighting the limited healthcare resources available to those outside of the capital.

In an effort to alleviate some of the disparity in health care, Partners in Health (PIH) and its sister organization in Haiti, Zanmi Lasante (ZL), opened a 205,000 square foot, 300-bed public tertiary care hospital in the Central Plateau of Haiti in March 2013, Hospital Universitaire de Mirebalais (HUM). HUM provides advanced medical care reaching more than 3.3 million individuals across the departments of the Central Plateau, Artibonite, Ouest, and countless others who come from other parts of the country. Practitioners at HUM treat approximately 700 patients a day and take a leading role in educating and training doctors, nurses, and health professionals. 20 Both HBM and HUM regularly collaborate with international aid organizations and medical teams in order to advance the care they can provide.

Pediatric surgical training in the local context is a necessary part of delivering equitable health care in Haiti. For the past 8 years, an international team of health care professionals from Children's Hospital Los Angeles (CHLA) and the Keck School of Medicine of the University of Southern California have worked closely with Haitian surgeons, anesthesiologists, pediatricians and nurses at HBM to provide advanced pediatric surgical care to infants and children roughly 5-6 times per year, 7-10 days at a time. This international partnership and collaboration led by Haitian born pediatric surgeon, Dr. Henri Ford, has resulted in significant improvement in the management of complex pediatric surgical patients. In 2014, 1475 operations were performed at HBM, of which 408 were inpatients less than 18 years of age and 187 less than 1 year of age. While most of the complex pediatric surgical operations at HBM were performed by international teams after the earthquake, now the majority of these operations are successfully performed by local surgeons without a pediatric surgeon. The success of these complex pediatric surgical procedures relies on the interactive training and skills transfer provided to Haitian practitioners through this ongoing international collaboration.

Evidence that global partnerships can result in the delivery of safe, advanced surgical care in a resource poor setting is illustrated by our experience involving the separation of conjoined twins in Haiti. This case underscores that delivery of advanced surgical care in LMICs through international collaborations is a component of achieving the highest attainable standard of health in order to contribute to sustainable development.

### **A case study - separation of conjoined twins in Haiti**

**Part 1: The birth of conjoined twins and pre-operative multidisciplinary preparation:** In September 2014, Dr. Christophe Millien, director of obstetrics and gynecology at HUM, diagnosed a triplet pregnancy by ultrasound, with two of the fetuses conjoined at the level of the abdomen, also known as omphalopagus. The frequency of conjoined twins is estimated at 1 in 50,000 gestations, but due to in utero demise the true

incidence is approximately 1 in 250,000 live births<sup>[21]</sup>. Separation of conjoined twins is a rare and complex medical procedure and those complexities are amplified in a resource-poor setting. Multiple attempts to find a hospital in the U.S. that would accept the mother, deliver the triplets and separate the conjoined twins were unsuccessful. Nevertheless, HUM and PIH held true to their mission of bringing the benefits of modern medical science to those most in need. They sought to assemble a team of experts to care for the conjoined twins and to perform the separation at HUM. Dr. Millien and his colleagues at PIH / ZL reached out to their international partners, seeking to create a collaborative multinational interdisciplinary team. After reviewing the ultrasound with the Institute for Maternal and Fetal Medicine at CHLA, Ford and colleagues concluded that the triplets would have a reasonable chance at survival if delivery could be delayed as long as possible to ensure viability of the fetuses and maturation of the lungs.

The triplets were born at 36 weeks of gestation via cesarean section at HUM giving the girls organs adequate time to mature. Dr. Ford, in conjunction with colleagues at HUM and CHLA, assessed the twins and formulated plan to ensure that the children would grow and meet their developmental milestones. As the conjoined twins progressed, the decision was made to separate the twins at HUM at six months of age. A team of U.S. and Haitian medical professionals were assembled to assist with the preparation and the procedure. Their goal was the delivery of safe, competent pediatric surgical and critical care to the conjoined twins while transferring knowledge and skills to Haitian medical professionals in order to advance local, self-sufficient care of Haitian children.

The first and arguably most important aspect of the separation was the pre-operative planning. Assembling a multidisciplinary team was key to the success of the procedure. The team included pediatric surgeons, a pediatric plastic surgeon, pediatric anesthesiologists, pediatric intensivists, operating room nurses, ICU nurses, and respiratory therapists from CHLA, Weill Cornell Medical Center, and Florida Hospital who partnered with the local expertise of multidisciplinary Haitian physicians in the specialties of surgery, anesthesia, pediatrics, OB/gyn, pediatric infectious disease, and nursing from HBM, HUM, and the GHESKIO center.

In addition to monthly visits to HUM to monitor the twin's progress, the team established a weekly teleconference with all the key stakeholders in Haiti and the U.S. to review the meticulous details regarding the separation and ensure that the equipment and expertise necessary for the safe and optimal peri-operative care of the twins were in place. The logistics of the operation, around-the-clock post-operative care, and team communication were greatly emphasized. The team was divided into two colors (yellow and red) to clearly delineate which practitioners would stay with each baby throughout the procedure. In May of 2015, once all concerns were properly addressed and the twins were sufficiently healthy for the procedure, the team was mobilized to Mirebalais, Haiti, to perform the first separation of conjoined twins in the country alongside their Haitian colleagues.

**Part 2: Intra-operative communication and teaching:** Direct transfer of knowledge and skills proceeded harmoniously before

and throughout the operation. Multinational anesthesia teams worked side by side to induce anesthesia and intubate the twins. Shortly after beginning, the operation was complicated by an intraoperative episode of cross circulation. This had been anticipated and the anesthesiologists promptly implemented the appropriate measures needed to resuscitate the twins. Expedient separation of the liver quickly remedied the problem of cross circulation and the twins remained stable throughout the remainder of the separation.

A momentous and inspirational moment in the operating room occurred when the final connecting tissue between the conjoined twins was separated. The twins were placed on separate operating room tables with respective color-coded anesthesiologists, surgeons, and OR nurses in place. The procedure lasted 7 hours and was a success for the girls and a unique chance for Haitian practitioners to work alongside American colleagues in an operation rarely performed in the most advanced hospitals in the world.

**Part 3: Post-operative care:** The timing of the operation coincided with the opening of the ICU at HUM, which provided an opportunity for training and skills transfer in critical care. Post-operatively, the twins were managed in the ICU by a carefully trained team consisting of Haitian and American intensivists, residents, nurses and respiratory therapists. The team was led by pediatric intensivist Dr. Peggy Han who meticulously carried out teaching rounds twice a day, having her Haitian colleagues present the patients. The girls were extubated within 24 hours and for the first time, their mother and father were able to hold them individually. Within two weeks, the girls were discharged from the hospital without any complication. Two-and-a-half years after the operation, the triplets and their parents are healthy and happy.

## Conclusion

**A call for collaboration and further advancement of pediatric surgical care in haiti:** Our experience illustrates the capacity to deliver safe, advanced surgical care and achieve the highest attainable standard of health within the constraints of a low-resource setting. Alma Alta recognizes the need to involve international collaboration in order to achieve higher standards of health. With likely over 2.5 billion children globally without access to safe surgical care, collaboration of knowledge and transfer of skills across cultures and surgical settings is imperative<sup>[7,8]</sup>.

Haiti has unique challenges to building surgical capacity. Although the earthquake in 2010 generated billions of dollars in funding and an outpouring of foreign medical aid to provide immediate short-term lifesaving interventions, the nation still lacks adequate infrastructure and resources to meet the population's ongoing medical and surgical needs<sup>[14]</sup>. It has a vastly underserved population, with fewer than half of the physicians per 10,000 than the LMIC average<sup>[17]</sup>. In addition, more than half of its population lives on less than one dollar a day<sup>[14]</sup>. Inadequate primary care systems result in delayed recognition of illness, late presentation and poor follow up of surgical patients. Our experience at HBM and HUM, along with reports from other LMICs, have shown that lack of adequate primary care, long travel times,

and cost of transportation have caused many children with surgically correctable diseases to have significant delays in diagnosis leading to increased morbidity and mortality<sup>[22-24]</sup>.

Outcomes for pediatric surgical procedures in other low-income countries show large disparities, especially regarding urgent procedures. In Uganda, intestinal atresia was found to have a 30% mortality rate compared to 4% in the Western literature<sup>[22,25]</sup>. Factors that contribute to pediatric surgical mortality include poor transportation, late presentation, inadequate equipment and facilities, insufficient manpower, inadequate documentation, and poor follow up.<sup>23</sup> Pediatric surgical outcomes are better in specialized centers, as outlined by the U.S. Task Force for Children's Surgical Care<sup>[26]</sup>. This illustrates the importance of specialized pediatric surgical training in LMICs, given the huge demographic strain placed on them by children under the age of 15,<sup>[8]</sup> in whom surgical disease accounts for 6-12% of all pediatric visits<sup>[22]</sup>. These challenges must be addressed in order to adequately care for Haitian children.

To achieve self-sufficient and sustainable pediatric surgical capacity in Haiti, long-term multidisciplinary educational relationships must be formed. Capacity must be built by training local surgeons and practitioners; visiting medical and aid teams can play a significant role during the transition to self-sufficiency<sup>[27]</sup>. Barriers to attaining this goal have been identified and must be addressed in Haiti. Lack of personnel trained in pediatric surgery, anesthesia and critical care, cost of patient transport, inadequate referral systems, social barriers, and inadequate infrastructure must be improved<sup>[28]</sup>. Academic medical centers have successfully formed partnerships with teaching hospitals in LMICs to improve capacity building. They have done so by recognizing the need for an approach emphasizing multidisciplinary clinical involvement concentrating on local needs while collaborating on research, measuring outcomes, creating longitudinal education programs and working within an existing training infrastructure<sup>[27-30]</sup>. Our experience at HBM over the past 8 years, and more recently at HUM, demonstrates that this approach is not only feasible, but can result in significant improvement in the quality of surgical care for infants and children with a variety of complex surgical conditions. By mobilizing teams across multiple academic medical centers to work alongside Haitian practitioners in order to provide safe surgical care for a complex pediatric surgical condition, the principle of a global standard of pediatric surgical care became a reality.

The first separation of conjoined twins in Haiti as an international multidisciplinary collaboration attracted media attention, local and international support and the recognition of the Haitian and U.S. governments. The success of this operation was a great source of pride for an entire country whose infrastructure had crumbled years earlier. The operation symbolized the advancement of healthcare in a nation that had to rebuild itself from significant damage. Indeed, it reflects in part the culmination of more than 7 years of capacity building by this international team to provide advanced pediatric surgical care in a country that has only 2 specialty-trained pediatric surgeons to care for 3-6 million children.

In addition to giving two Haitian children the opportunity to live a normal life, the purpose of performing the surgery in Haiti was to stimulate momentum for providing advanced, local pediatric surgical care. The separation of the twins is like-

ly one of the most complex pediatric surgical cases that have been performed in Haiti and allowed for the transfer of knowledge and skills to Haitian practitioners in order to advance local self-sufficient care and delivery of equitable health care in Haiti. Through the precedent already established at HBM and HUM, the conjoined twins separation, as well as ongoing reinforcement of acquired knowledge and skills through frequent hands on interactions, we hope to improve the ability of local practitioners to deliver advanced pediatric surgical care to Haitian children in a self-sustainable model. While our work promoting pediatric surgical care in Haiti is far from complete, we hope the first separation of conjoined twins in Haiti leaves a legacy of knowledge, teaching, communication, collaboration, and pride in caring for Haitian children.

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### Author Contribution

All authors contributed to the design and/or the planning, separation of conjoined twins, and follow up care. Dr. Ford and Dr. Golden contributed to data collection. Dr. Ford, Dr. Golden, and Dr. Linden wrote the manuscript and all authors contributed to editing and revising the manuscript

### Declaration of Interests

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