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Pediatric Urology and Global Health: Why now and how to build a successful global outreach program

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Introduction: What is Global Health?

Global health is a term that has many definitions in the literature and is often used interchangeably with international health and global public health. In 2010, Beaglehole and Bonita proposed the following definition for global health: “collaborative trans-national research and action for promoting health for all.”¹ The health in global health can refer to overall health or any of the full gamut of medical conditions (i.e., hypertension, diabetes, and infectious diseases) or congenital anomalies. While some congenital anomalies can be managed medically, many will require “action” such as surgical correction which can range from commonly performed surgeries to complex reconstructions. Unfortunately, the vast majority of severe congenital anomalies, up to 94% as estimated by the World Health Organization (WHO), occur in low and middle-income countries (LMIC) where families and governments are often resource-constrained and where surgical access may be difficult.²

In order to alleviate this large burden of disease on LMIC, the Sixty-third World Health Assembly in 2010 recommended that member countries not only “build capacity” to prevent

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and treat children with birth defects but also “promote international cooperation” to combat these disorders.³ Despite this call to action, the WHO and WHA do not give any guideline on how best to form these international collaborations or how to monitor success. **In this article, we discuss strategies with which to optimize care for complex surgical diseases on the international scale including ways to enhance regionalization, collaboration, and surgical education to accelerate learning curve limits with rare diseases.** By using bladder exstrophy as a model disease and highlighting the work of the International Bladder Exstrophy Consortium (IBEC) as a case report, the importance of these key elements as well as team building, long-term invested commitment, surgical coaching and mentorship will be emphasized.

The Surgical Burden of Global Health

Despite decades of being under appreciated, in part due to the lack of accurate estimation, the surgical burden of disease as a component of global health has recently garnered focus.^{4,5} In 2007 it was estimated that almost half of the world’s population lacked access to basic surgical care and recent estimates are as high as 5 billion people worldwide.^{6,7} Weiser and colleagues analyzed surgical volume in over 50 WHO member states from 2004 to 2012.⁸ While the authors note that surgical volume growth rate was highest in the most resource poor countries, less than 30% of all surgeries worldwide take place in these countries, which account for over 70% of the global population.^{8,9} Furthermore, the costs of surgical disease on lost economic output are highest in LMIC and are estimated to reach over 1% of the total gross domestic product (GDP) for these countries by 2020.¹⁰ Given these staggering statistics and the inequitable distribution of surgical diseases, the need for a global health focus on surgery^{11,12} is well justified and has the potential to not only decrease morbidity and mortality but also improve the economic situation and development of LMIC.

The case for pediatric urology as a global health priority

Global health surgical initiatives can provide general surgical care for common conditions or offer disease/condition specific (i.e., cleft lip and palate) surgical intervention, often by subspecialists. Pediatric urology with its variety of congenital malformations represents an ideal field for both types of global health surgical initiatives, especially given that genitourinary (GU) tract anomalies are 5-10 times more common than cleft lip and palate.^{11,12} In fact, congenital anomalies of the GU tract are the 3rd most common group of non-chromosomal congenital anomalies behind congenital heart defects and limb defects.¹³

When considering specific pediatric urologic conditions, the number of affected infants and children worldwide are even more staggering. Hypospadias itself is one of the most common birth defects and occurs in 1 of every 150-300 live male births; the number of new hypospadias cases in sub-Saharan Africa alone with an estimated 40 million live births per year dwarfs the number of new cases in the United States.¹⁴⁻¹⁶ Likewise, in India, where the pediatric population is almost 500 million, there is estimated to be over 58,000 new congenital GU malformations each year with at least 15,000 of these new cases being hypospadias.¹⁷ While several other pediatric urology conditions, such as inguinal hernias and cryptorchidism, are similar to hypospadias in having higher prevalence rates, some

specific GU anomalies, including bladder exstrophy-epispadias complex (BE) and cloacal malformations, are rarer and often require complex surgical reconstruction.

Despite the lower incidence rates, even these rare GU conditions can account for a substantial number of new cases annually given the higher birth rates globally, especially in LMIC. For example, the incidence of BE is estimated to be 1 in 50,000 live births; while this would lead to only ~80 new cases of BE in the United States per year, based on live birth rates India would have >500 new infants born with BE per year.¹⁷⁻¹⁹ Furthermore, prenatal care is often limited in LMICs and few pregnancies are electively terminated for medical reasons leading to higher birth rate of neonates with undiagnosed congenital malformations. Despite these numbers, the availability of trained pediatric urologists globally is critically low, especially in sub-Saharan Africa where there are less than a handful of pediatric urologists for a population of nearly 500 million children.^{14,20}

Thus the variety of congenital anomalies in pediatric urology, mixed with the sheer prevalence of these conditions worldwide and the lack of access to trained specialists in most LMIC, underscores the critical need to consider pediatric urology as a surgical global health priority. As mentioned earlier, despite recognizing the need for international collaborations to prevent and treat congenital anomalies, the WHO and WHA provide no guideline for how best to accomplish these goals.

Types of Surgical Global Health Programs

In practice there are several different surgical “medical missions” or outreach program models that have been implemented or evolved over time to meet various global health needs. These various programs vary widely in organizational structure, overall goals or mission, ability or desire to establish a sustainable local infrastructure, frequency of contact and follow up, and commitment to surgical education and training. Given these differences, especially in overall philosophy and resources, the ability of each program to have a lasting impact on the local healthcare system also varies dramatically.

One useful way to categorize surgical global health programs is offered by Dr. Ofer Merin in a chapter on the evolution of surgical humanitarian missions.²¹ Dr. Merin describes three types of international surgical health projects: clinical, relief, and developmental projects.²¹

Clinical projects are “preplanned delegations” that focus on chronic diseases or target specific diseases. These programs either go to various underserved locations across the globe with the goal to provide care for surgical conditions or send patients to centralized care centers to receive the care they need. Common examples include missions to provide general surgical care, repair facial deformities, cataracts, and even congenital heart disease.²¹⁻²⁴ The primary focus of these projects are to provide quality care to at-need patients and not on building capacity or training local physicians. Often times, these projects function as a “one-off” with limited to no follow up and location may rotate. These projects can be sponsored by medical or academic institutions, international organizations (i.e., the United Nations, WHO, and International Committee of the Red Cross), governmental organizations, or non-governmental (often not-for-profit) organizations.²¹

Relief projects are those that focus on rapidly responding to natural disasters or violence from wars.²¹ These projects are often short-term and involve assembling surgical teams quickly after the inciting event. The goals of these projects can be to either fill-in for or supplement a local medical system and are often situational dependent.

Developmental projects are based around a long-term framework with the primary aim to build local surgical capacity by collaborating and partnering with local medical personnel to provide surgical training and education.²¹ The emphasis of these projects is on sustainability through the strengthening of the local infrastructure and teaching of local surgeons such that they become self-sufficient and adept at treating the surgical condition(s) of focus. These programs, like clinical projects, can provide general surgical skills for a variety of conditions or have a specific disease as the primary focus with expertise provided by sub-specialists. Importantly, these projects are based on repeated visits, often over years, which allows for long-term follow up of surgical patients, increased accountability and monitoring of outcomes. This last point cannot be over-emphasized as one critique of “one-off” clinical outreach projects is the lack of follow up and thus the inability to ensure surgical success and proper treatment of post-operative complications. By committing to the long-term sustainability of the program, humanitarian surgeons engaged in developmental projects can overcome this limitation and continue to honor the “Do no harm” pillar of the Hippocrates Oath.²¹ These projects also enable ongoing coaching or mentoring of the local surgeons by the international team members.

The number of surgical global health programs that have embraced the “teach a man to fish” philosophy of the developmental model has grown steadily over the past couple of decades. Examples of these types of programs exist in many pediatric surgical sub-specialties including cardiovascular surgery, plastic surgery, otorhinolaryngology (ENT), ophthalmology, orthopedics, neurosurgery, and urology. Combination programs between plastics and ENT include SmileTrain and Operation Smile, both of which strive to provide a sustainable model to “empower local doctors...in their own communities.”²⁵⁻²⁷ Many congenital heart disease global initiatives have also moved away from the clinical model and towards a developmental one including Save a Child’s Heart and Heart to Heart Global Cardiac Care whose mission is to “develop self-sustaining medical programs in areas of need.”^{22,28}

In pediatric urology, surgical global health projects range from one-time clinical missions to formal developmental model programs. According to a recent survey by the Global Philanthropic Committee (GPC) over 90% of urologists in the AUA (American Urological Association), EAU (European Association of Urology), and SIU (International Society of Urology) were interested in global volunteer services with over 50% performing some form of voluntary philanthropic activity in the past 10 years.^{29,30} Interestingly, the vast majority of volunteering urologist participated in short term clinical projects and not with a formally established group such as IVUmed (formerly International Volunteers in Urology), the WHO, or Doctors without Borders.²⁹ In fact, the majority of volunteers were unaware of the services provided by these organizations for surgical global outreach.²⁹ Given the high level of interest in international volunteerism, yet lack of knowledge about how to get involved,

there is need to both publicize available opportunities as well as share information on how to successfully implement a global health program.

Global Health Programs in Pediatric Urology

There are several programs available for the pediatric urologist interested in global health outreach. One of the most well established program is IVUmed which was founded in 1995 by Dr. Catherine deVries.^{12,31} IVUmed has a long track record of excellence and serves as a prime example of an organization that can be utilized by urologists interested in medical volunteerism for a one or two week commitment.³¹ A quick search of IVUmed's website provides a list of upcoming international missions with locations, dates, focused urologic area and needed personnel for each trip.³¹ These positions for the most part are not recurring and one can sign up via an online application. While volunteers may go to a specific international location only once, IVUmed as an organization provides a long-term commitment to each location with an overall mission to "make quality urological care available worldwide."³¹

IVUmed provides global urological care in multiple areas including reconstructive, oncology, female urology, and pediatrics. In pediatric urology, IVUmed international outreach programs provide the breadth of surgical care with some workshops focused on a specific condition or type of case. By starting with a common condition such as hypospadias and providing more advanced training over time through continued interaction, IVUmed helps build surgical capacity at each location.¹² Although the same volunteer surgeons do not necessarily return each time, the framework and overall program plan is anchored by IVUmed to ensure long-term success.

An alternative approach for global health outreach to the programs currently available, such as those offered by IVUmed, is to establish a *de novo* collaboration between an academic research center (ARC) in a high-income country (HIC) and a hospital/local surgical team in a LMIC. While starting such a collaboration from scratch may seem daunting, these programs when based on the solid foundation of a mutual, shared vision of local surgical training, can be fruitful and lead to marked increases in surgical capacity and surgical learning in both directions. These programs must be based on continued interaction between the HIC ARC surgical team and the same local LMIC team, and as such are dependent on strong team-building and long-term personal commitments by each member. While these types of programs can offer general surgical care, they are particularly useful for the care of complex conditions since they allow the same surgical teams to provide care and monitor outcomes over time.

One example of a program that fits into this category is the International Bladder Exstrophy Consortium (IBEC) which was founded by Drs. Richard Grady and a co-author (ARS) from two ARCs in the United States in collaboration with the Department of Pediatric Surgery at the Civil Hospital and B.J. Medical College in Ahmedabad, India in 2009.¹⁸ IBEC currently includes a multidisciplinary team from 3 ARCs both in the United States and Qatar (Seattle Children's Hospital, Seattle, Washington; Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; Cincinnati Children's Hospital, Cincinnati, Ohio; and Sidra Medicine, Doha,

Qatar) that travels to Ahmedabad for 8 days annually to provide continued hands-on surgical training of the local pediatric surgery team as well as long-term follow up of treated patients. A recent publication by Joshi and colleagues evaluated the IBEC program and determined that not only was long-term follow up and retention feasible within the infrastructure of the collaborative model, but that the outcomes of these complex reconstructive procedures for BE and epispadias were comparable to those at ARCs in HIC.¹⁸

Key Principles for Success

Based on a review of the missions and structures of several surgical global health projects that fit into the developmental model framework, including the personal experiences of three of the current authors with IBEC, we propose a set of key principles that we believe are critical for success of surgical outreach programs.

Collaboration/Partnership with Local Team

The most important first step in developing a global health surgical outreach program is selecting an appropriate site and establishing a local team with which to partner. The key is not just in collaborating with, but in partnering with the local team: surgeons (often pediatric general surgeons), anesthesiologists, and nurses. These surgical partnerships allow staff and resources from ARCs in HIC to combine with the high volume and local surgical team in a LMICs. The partner site (i.e., hospital) must have appropriate surgical equipment, staff, capacity for post-operative care, and ability to provide long-term follow up. The local surgical team must be included in the global health program as equal partners from the start as this will allow for the eventual self-sustainability of the local surgical program and for building of surgical capacity. After all, much of the post-operative care including near term complications, will be managed by the local team and thus both the international and local groups must be devoted to the overall mission. Without a true sense of partnership, one or both sides may feel less invested and thus less dedicated to the long-term success of the program. Another key point to improve the outcomes of the global health program is early commitment or buy-in from the local hospital administration. If the local hospital administration is committed to the program and provides the necessary infrastructure to support the program, then the probability of success will only increase.

For IBEC, the partnership between the American ARCs and Civil Hospital has allowed for consistency of the team which makes possible the long-term investment in both surgical training and delivering of high quality patient care. The ultimate goal must be to build surgical capacity in LMICs with limited access to surgical sub-specialists, and IBEC is one approach to comprehensively address complex conditions in pediatric urology through collaboration between a committed traveling team and a strong local team.¹⁸

Building a Multidisciplinary Team

Perhaps equally as important as finding a committed international site and local team, is building a strong traveling team. The components of the team must ensure appropriate care for the patient through the surgical care pathway from pre-operative evaluation to post-operative management. For pediatric urology in general, the multidisciplinary team at

minimum should include personnel specialized in pediatric urology, pediatric anesthesiologist, and pediatric nursing. The focus on team building is also emphasized by IVUmed which describes a typical team as consisting of 2-3 surgeons, 2 anesthesia staff, 2-3 nurses, and 1-2 support personnel for research.¹²

As a part of IBEC, given the focus on BE, the team also includes a local pediatric orthopedic surgeon and health care advocates from patient advocacy organizations (specifically from the Association for Bladder Exstrophy Community [A-BE-C]).³² The team has also included pediatric urology fellows and research fellows who have helped record and monitor outcomes. Two years ago, a nurse specialized in the post-operative care of pediatric patients from one of the ARCs joined the IBEC team and added tremendous value for education of both local nursing teams as well as patient families. A well-built multidisciplinary team is based on mutual respect by each member towards the important roles played by all other members. This congeniality among team members cannot be over-stressed especially when building a team across different ARCs as the coordination will become more complex and need for frequent communication will be essential for success. All team members must have enthusiasm or “buy-in” for the overall mission of the program and be committed in the long-term in order for the program to have sustainability and achieve the pre-defined goals.

Defining the Mission: A Shared Vision

The importance of defining the mission or goals of the global health surgical program early serves multiple purposes. As suggested in the previous two sections, building a lasting partnership and forming both the traveling and local surgical teams is in large part dependent on having a common mission or goal. If the traveling team and local team have different ideas for how the program will function or what the long-term goals are, then this can lead to not only failure of the program but poor outcomes for patients. A shared vision will ensure that all team members are working towards the same outcome and committed to the success of the program.

As mentioned previously, IVUmed clearly defines its mission as providing access to high-level urological care for all people worldwide. The motto of IVUmed is “Teach One, Reach Many,” and the goal of surgical training and education of local physicians is front and center on the group’s website³¹. Likewise, the mission of IBEC is to provide quality care for a complex pediatric urology condition while engaging in surgical training of the collaborating pediatric surgeons at Civil Hospital. In addition to surgical training and education of the local team, other goals, such as monitoring of patient outcomes and other research endeavors, should also be defined early on and preferably before the program starts.

Emphasis on Surgical Education, Training, and Coaching

A central tenant of any global health surgical program that aims to increase local surgical capacity must include surgical training and education of the local team. Without this commitment to training, the program will not be sustainable and the ability to provide quality care in underserved areas will end with the conclusion of the global health project. By utilizing all of the key principles already mentioned, the collaboration between ARCs from HIC and local hospitals in LMIC can result in development of a high-quality center

with an experienced local surgical team that can treat complex surgical conditions. Although this transformation may take years, this investment in surgical education and training is what leads to building surgical capacity and regionalization of the care of complex conditions. Regionalization of surgery by limiting high-risk surgeries to centers with high-volumes has been suggested as a quality improvement strategy in HICs based on lower mortality rates at high-volume centers.^{33,34} In essence, the ultimate outcome of a successful global health surgical program devoted to surgical training is the regionalization of the surgical care of complex or specialized conditions in LMIC such that the outcomes rival those of the ARCs in HIC. Through regionalization of care, the local team is often exposed to a high volume of complex cases which allows for not only more rapid accumulation of experience but also the ability to report outcomes of larger patient series than even the sponsoring ARCs.¹⁸

Even after the local surgical team becomes adept at performing the specialized surgical procedures, there is a role for continued surgical coaching or mentoring in the operating room. The idea of surgical coaching has gained some traction recently in the literature, as some have questioned why surgeons do not have coaches while professionals in other disciplines (including music and sports) that also emphasize performance do.^{35,36} To provide context, when using the term surgical coaching, we are not referring to teaching or mentoring of residents and fellows by faculty, but the actual coaching of attending surgeons by peers or more senior faculty members. The goal of surgical coaching and teaching is to provide continuous professional development of surgeons³⁶ and this mentality can also be thought of as part of a component of a successful global health program. By providing coaching, the surgical technique and procedures can be further standardized and outcomes can be measured. This allows for the local surgical team to not only become experts but also provide valuable research results to the international community.

Furthermore, the international community can also directly benefit from the surgical education at the global health site via expanded access to the surgical training program. Once the global surgical health program has become well-established, the program can be opened up to host surgeons from other nations. This is particularly beneficial for rare, complex diseases, such as BE, where exposure even in HICs can be limited due to regionalization and from, possibly, early termination. Over the past several years the IBEC program has hosted more than 20 surgeons from nations as diverse as the USA, Canada, Germany, Spain, Brazil, Qatar, Iran, Turkey, Uganda, and Kenya. These international surgeons benefit from observing a high concentration of BE surgical cases over a short period of time and are able to directly interact with the surgeons who are actively teaching. Impressively, these surgeons in just one week will be exposed via IBEC to more BE surgeries than almost all graduating pediatric urology fellows in the USA participate in during their entire fellowships. Interactions between the global health program and international surgeons also offers additional benefits. In partnership with ABeC, Ugandan surgeons have traveled to India in consecutive years with their BE patients to observe surgery and participate in post-operative care. These surgeons are now actively planning on creating a center of excellence following the IBEC model in Africa.

Interaction with Local Policy Makers and Government Officials

The traveling healthcare team is in a unique position to engage with local policy makers and government officials to ensure adequate funding and resources to the hospitals in the LMICs that participate in the global health surgical program. While funding for global health projects vary in origin and amount depending on the nature of the project, goals, and long-term commitment, the local hospital and government also have resources that can often be utilized to create a working partnership with equal investment in the program. Although this may not seem obvious initially, this partnership will be critical for continuation of the program and building relationships based on trust. By monitoring patient outcomes and successes from the global health program and reporting these data to local officials, both the impact of the program and dedication of the traveling and local surgical teams will be emphasized and likely foster further interest and support for continued or additional resources.

The importance of this key principle is clear in the work done by both IVUmed and IBEC. IVUmed recognized the need for a “long-term memorandum of understanding” between the traveling team and both the hospital administration and the country’s ministry of health.¹² Likewise, IBEC has actively engaged with the hospital administration at Civil Hospital including the superintendent and other local government officers in the Indian state of Gujarat.

Commitment to Quality Improvement

In addition to providing surgical care to patients, an essential component of a high-impact global surgical health program is the ability to monitor patient outcomes, report these outcomes, and initiate quality improvement (QI) projects. The ability to implement QI projects is dependent on many of the principles already described and should not be overlooked when developing the global health partnership. These projects have the potential to impact both the care of local patients as well as provide important research data that can impact health care abroad. QI projects often take the form of small, incremental changes to care and are based on previously collected data and research from the global health program. In fact, the ability to implement QI projects depends on having a strong commitment to research and monitoring surgical outcomes. As part of IBEC, research personnel have traveled with the international team to record and collect outcome data. This allows reporting of the data and assessment of program success as well as identification of areas for improvement. For example, after the initiation of IBEC, the host team began a process of nutritional status assessments preoperatively and a program to ensure adequate caloric intake and nutritional goals assessments post-operatively. Similarly, an institutional database was created to ensure that comprehensive patient data from surgical procedure performed, to radiological studies, to urodynamics assessments was properly scored and tabulated.

Dedication to a Long-term Commitment

Finally, the ultimate success of a global health surgical program depends on the dedication from both the traveling and local teams to a long-term commitment. This commitment allows for sustainability through surgical training and coaching, and for improvements in surgical technique and innovation through research and reporting of outcomes. Both in

IVUmed and IBEC, emphasis on the importance of repeat visits to the host site and the long-term investment required to build surgical capacity and decrease the burden of global disease remain hallmarks of the model. Currently, IBEC is in its 10th year with almost all members having participated in at least 6 trips, and the collaboration is entering a phase of expanding the surgical armamentarium related to long-term exstrophy care, and also fulfilling a global education role with the unique opportunity of exposing surgeons from HIC and LMIC to a high volume of exstrophy, diagnosis, treatment and follow up care over an accelerated time continuum.

Securing Financial Support

Global health surgical programs are expensive to initiate and to continue, thus one must consider from the beginning the costs involved and the financial options that exist. In addition to travel expenses (i.e., flights, lodging, food, and local transportation) for the ARC team, other costs include surgical supplies (i.e., sutures, sterile gloves, special instruments if needed, catheters, and bandages/dressings), operating room space and time, hospital space for pre- and post-operative care, and time requirement for local healthcare personnel from administration to nurses to surgeons. Furthermore, each traveling ARC team member must consider the loss of revenue involved with leaving their home institution and not participating in clinic or operating during the time abroad. To support the finances involved in a global health program and the loss of revenue, several options are available. Hospital administrative support and commitment to global health programming may be leveraged depending on institutional priorities, philanthropic outreach may serve to bolster divisional or departmental travel allotments, and/or efforts may be expended to endow a chair for international global health that will reliably generate revenue. At a national level, government support or grant support from foundations such as the Gates Foundation or foundations with specific interests relevant to the global work (i.e., ABeC), are possible sources for financial support, including federal bodies if research is relevant. Additionally, not-for-profit (NFP) organizations may offer support for specific components of the global health outreach. For instance, some NFP organizations gather surgical supplies or clothing which may be useful during global health program visits. Interacting with these groups can decrease the financial burdens/costs to the traveling ARC team.

Conclusion

Global health programs are needed in multiple areas of medicine and surgery to help ease the burden of global disease. Pediatric urology is an ideal field for global health programs as genitourinary diseases account for a large proportion of congenital diseases and access to surgical sub-specialists is lacking in most LMICs. Pediatric urologists interested in global health outreach can volunteer through established programs or build de novo collaborations. By following several key guidelines with particular emphasis on a long-term commitment and surgical training of the local surgical team, global health partnerships between ARCs from HIC and hospitals from LMICs can lead to a sustainable model for increased surgical capacity.

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Key points:

- Pediatric urology is an ideal field for global health programs because genitourinary diseases account for a large proportion of congenital diseases.
- Pediatric urologists interested in global health outreach can volunteer through established programs or build de novo collaboration.
- By following several key guidelines with particular emphasis on a long-term commitment and surgical training of the local team, global health partnerships can lead to a sustainable model for increased surgical capacity.

Synopsis: Global health programs in pediatric surgical fields are needed more than ever to ease the global burden of congenital anomalies. Pediatric urology is an ideal field for global health programs as genitourinary diseases account for a large proportion of congenital diseases and access to surgical sub-specialists is lacking in most low and middle income countries. By following several key guidelines with particular emphasis on team building, visiting and local team collaboration, long-term commitment and surgical training, global health partnerships can lead to a sustainable model for increasing surgical capacity.

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