



Hugh Greenwood International Lecture

The burden of pediatric surgical disease in low-resource settings: Discovering it, measuring it, and addressing it



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ABSTRACT

Global surgery has come of age as an emerging discipline poised to impact health care worldwide with a concerted plan of action and wide stakeholder support. Much less can be said about global pediatric surgery, despite a growing awareness of the global burden of pediatric surgical disease. The author describes his exposure to this burden of disease as a pediatric surgeon working in resource-limited countries in Africa and outlines his personal journey from recognizing the burden to measuring it and eventually attempting to address it. The article, based on the Hugh Greenwood International Lecture at the 2015 BAPS Congress, reviews what is known so far within global pediatric surgery, what is currently happening, and what lies ahead.

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Global surgery has come in recent years to the forefront of attention in surgical society meetings, training programs, and lay media. How did the year 2015 come to be dubbed “the year of global surgery”? Is this just a fad, media hype or a solid trend in surgery? Finally, if this is a significant new paradigm, how can we as pediatric surgeons be part of it? I will attempt to address these questions within our realm of pediatric surgery, following the sequence in which I have encountered these concepts in my own life overseas: firstly discovering the global burden of pediatric surgery, then trying to measure it, and finally struggling with how to address it.

1. Discovering the global pediatric surgical burden

In my personal career, I discovered global pediatric surgery through BethanyKids, a small faith-based organization which I joined in 2001 and have worked with since.

BethanyKids' lofty mission is “healing African children, transforming lives”. It attempts to do that in several ways: by funding and performing pediatric surgical procedures for children who would otherwise not be able to afford them, by providing surgical rehabilitation, by training African pediatric surgeons, and by working alongside them in their home countries. Over the past 10 years the organization has funded and performed more than 20,000 surgical procedures on children, spanning general surgery, urology, neurosurgery, and plastic surgery. In neurosurgery alone, a steady volume of almost 1000 yearly operations for spina bifida and hydrocephalus identified us as the referral place for children with these conditions not only in Kenya but across much of sub-Saharan Africa. From its original base in Kijabe, Kenya BethanyKids

has found itself as the sole provider of pediatric surgical care for several years in the Dadaab Refugee Camp in north-east Kenya, and has organized regular outreaches into Somaliland. BethanyKids at Kijabe Hospital (BKKH) also became the site of East Africa's first pediatric surgical fellowship program, which has so far trained 6 pediatric surgeons, all of whom are now practicing in their home countries (namely Kenya, Madagascar, Ethiopia, Tanzania, Uganda, and Sierra Leone).

During the early years of practice in Kenya, I have come to recognize the problems of pediatric surgical practice in limited-resource settings as the so-called “problems of the too's”: *too many* children in need of surgery, who live *too far* to get timely care, and are *too poor* to afford this care. Therefore they arrive *too late* to surgical facilities, where there are *too few* trained professionals to care for them, thus ultimately resulting in *too little* being done. The images of babies crowded in one ancient incubator, or children brought to our clinics in wheelbarrows or even cardboard boxes, in various states of malnutrition, sepsis or simple medical neglect haunt me to this day. Besides, what does a pediatric surgeon do with a 2-week-old baby with open gastroschisis, a 15-year-old girl with unrepaired rectovestibular fistula, or a 21-year-old man with fresh bladder exstrophy or untouched ambiguous genitalia? Beyond the surgical challenges, how does he or she handle the crass injustices of almost universal lack of access to health care, available yet inaccessible lush resources in private facilities, or horrendous complications resulting from care that was “too little, too late”? How does one deal with the ultimate disease affecting our little patients, the “disease” of poverty?

Like many others in situations similar to mine, I took a deep breath, prayed for help, and got to the job. I learned how to operate safely on conditions that I had never cared for in North America — such as hydrocephalus and spina bifida, cleft lip and palate, hypospadias and bladder exstrophy. We needed to do that in order to address the broad spectrum of this “*other* pediatric surgery” which I was encountering in Africa —

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one significantly different from everything I had been taught or knew in North America, one created by scarce resources. In a cruel form of “survival of the fittest” caused by very limited access to surgical care, most babies with potentially fatal urgent neonatal conditions (diaphragmatic hernia, esophageal atresia, gastroschisis and the like) simply died in their homes before reaching any facility, while those with nonfatal conditions (such as hypospadias, cleft lip/palate, or female anorectal malformations) survived for years with their unoperated conditions, resulting in a huge burden of chronic surgical disability. Besides the burden of unoperated congenital surgical disease there were also many acquired surgical conditions, such as trauma and burns, which generated their own disability. Finally, late presentation for care meant advanced disease, concomitant malnutrition, often more complex procedures needed, and an increased likelihood of postoperative complications.

In the process, we started training through BethanyKids as many African surgeons in pediatric surgery as we could, and supporting them after graduation in their home countries. Upon graduation these trainees often became the very first or second pediatric surgeon in countries of tens of millions of people – thus their own work ahead was overwhelming.

Then I decided to learn all I could about this global burden of pediatric surgery I had so far recognized.

2. Measuring the global pediatric surgical burden

Traditional mortality-based statistics clearly do not capture the full picture – they have nothing to say about the 15-year-old girl who had spent her entire life in shame and isolation, stooling through her vestibule. The Global Burden Of Disease (GBD) study uses a “newer” metric – the DALY (disability-adjusted life year) [1]. This metric included not only mortality from disease (years of life lost, YLL) but also morbidity (years lived with disability, YLD) (Fig. 1). The GBD study has in progressive iterations over the past two decades estimated the burden of disease (BoD) globally by geographic region and health state, vividly illustrating the disparities in BoD between high- and low- and middle-income countries (LMICs) [2]. It has also successfully identified the primary etiological factors responsible for these health states [3]. Surgical conditions in general cut across all disciplines and are estimated to account for 30% of all BoD [4]. Congenital anomalies were ranked 14th globally, comprising 1.9% of the total global BoD and accounting for a staggering 52 million DALYs [5].

However the GBD data were primarily global, regional, or country-based - hence too granular for institutional use. Furthermore almost no pediatric surgical conditions were identified within it. In order to be able to measure the BoD in children we needed disability weights (DWs) for common pediatric surgical conditions in LMICs. We therefore set ourselves to estimate these, using mixed psychometric and economic methods similar to those used by the GBD study, but on a much smaller scale – in both Canada and Kenya. Our study results had good reliability, and the weights were surprisingly similar across countries (Fig. 2) [6]. Armed with these pediatric surgery-specific

disability weights, we were then able to estimate the BoD from congenital malformations for entire countries, and for unique settings like refugee camps [7,8].

Bickler et al. [9] had previously applied DALYs to surgical disease by dividing the burden of surgical disease into *met* (already surgically averted DALYs), *unmet* (avertable DALYs), and *unmeetable* (unavertable DALYs). We expanded that key concept to include a fourth component: the *delayed met need*, the burden suffered by a child who has already lived for years with her disabling surgical condition [10]. These are DALYs which are “lost” and irreversible – thus highlighting the urgency of the plea for surgical care. We estimated such delayed DALYs not only in low-resource settings, but uncovered them in high-resource settings as a vivid reflection of surgical wait lists [11] (Fig. 3).

Yet DALYs alone appeared insufficient to paint the full picture in global surgery, and we kept looking for complementary metrics [8]. We attempted to measure surgical coverage of geographical areas and the backlog of unoperated surgical patients. This led to startling results – such, for instance, that BethanyKids’ “great” surgical work in the refugee camps was only addressing 10%–20% of the actual burden [6], and that globally there was a backlog of around 1 million children waiting to have their cleft lip/palate repaired [12] (Fig. 4). Finally, we applied cost-effectiveness and health valuation methods to demonstrate, alongside other researchers, the high cost-effectiveness, in \$/DALY, of a range of simple and complex pediatric surgical procedures – often surpassing the cost-effectiveness of common immunizations or medical therapies [6,10] (Fig. 5). As for economic impact, valuation methods revealed that the global cleft lip/palate work done by one large cleft charity had resulted in economic benefits in the range of several billions of US dollars annually! [13]

3. Addressing the global pediatric surgical burden

The scale of the global BoD estimated to be caused by pediatric surgical conditions is so enormous that the question of actually tackling it loomed larger than ever before. The very existence of huge surgical backlogs was proof that many of the historical methods of addressing the burden had proved inadequate. Motivated and pushed by the Millennium Development Goals (MDGs), government institutions and facilities have made progress across LMICs in primary care provision – while the surgical burden had remained largely untouched. Charitable “platforms”, originally in the form of mission hospitals, had faithfully served across resource-limited areas with good, albeit limited, results. They were historically replaced, in part, by a virtual tsunami of “temporary platforms” [14]: surgical safaris, camps, and campaigns. Despite the enormous popularity these have enjoyed in the past couple of decades, evidence of their quality and sustainability is lacking. More effective appear to be the newer permanent platforms – “vertical” or “niche” specialty hospitals with foreign support, focusing on one condition or group of diseases – such as obstetric fistula, cataract, club foot, or cleft lip/palate [14].



Fig. 1. DALY infographic. This file was derived from: DALY disability affected life year infographic.png.. Licensed under CC BY-SA 3.0 via Wikimedia Commons –https://commons.wikimedia.org/wiki/File:DALY_disability_affected_life_year_infographic.svg#/media/File:DALY_disability_affected_life_year_infographic.svg.

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