



Congenital anomalies in the context of global surgery



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ABSTRACT

Surgery is increasingly recognized as an essential component of global health development. This article will review the state of global pediatric surgery, utilizing congenital anomalies as a framework in which to discuss the promise of pediatric surgery in reducing the global burden of disease. Congenital anomalies are responsible for a substantial burden of morbidity and mortality in low- and middle-income countries (LMICs), as well as significant emotional and economic harms to the families of children with congenital anomalies. Limited pediatric surgical capacity in many LMICs has culminated in a devastating burden of avertable disability and death. Pediatric surgery is an effective and cost-effective means to reduce this burden. Pediatric surgeons must continue to drive the growth of global pediatric surgery by engaging in clinical practice, educational partnerships, and research initiatives.

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Introduction

Surgical disease is responsible for an estimated 11–30% of the global burden of disease.¹ In the 2010 World Health Organization (WHO) Global Burden of Disease Study,² which described the worldwide distribution of morbidity and mortality, surgery was essential to the diagnosis and treatment of patients in all of the disease categories described (injury; non-communicable diseases; communicable, maternal, neonatal, and nutritional diseases), underscoring surgery's role as a pillar of healthcare in both low- and middle-income countries (LMICs) and high-income countries (HICs).^{3–5} Overall, 321.5 million more inpatient surgical procedures are needed to meet the global need; the surgical need in terms of top disease indication varies between regions and countries, further underscoring the importance of surgery across healthcare systems, regardless of individual regional or national health priorities.³

Historically, surgery was considered “too costly and too complex” for inclusion in health development projects in LMICs, “a luxury to be afforded only by the wealthy elite.”⁶ This misconception, in combination with vertical approaches to public health which focused on particular diseases, largely rendered surgery a *persona non grata* in the world of health development.^{6,7} However,

as mounting research reinforces that surgery is and should be considered as an integral component of improving global health and well-being, global health stakeholders and leaders have increasingly recognized the importance of surgery in reducing the global burden of disease, and have initiated projects to support the growth of global surgery.⁷

Much work remains to be done before global surgery can live up to its promise. 67% of the world's population, or approximately 4.8 billion people, do not have access to surgical care, when access is defined by availability, timeliness, safety, and affordability.⁸ In some regions of the world, such as sub-Saharan Africa and Southeast Asia, over 95% of the population does not have access to surgical care.⁸ Among the LMICs for which national surgical workforce data is available, the density of general surgeons ranges from 0.13 to 1.57 per 100,000 population, and the density of anesthesiologists from 0 to 4.9 per 100,000 population.⁹ Foreign investment in the development of surgical systems is also limited. The Institute for Health Metrics and Evaluation's Development Assistance for Health Databases suggests that the total assistance targeted to surgical initiatives in LMICs by HICs is relatively minor, representing < 1% of the total developmental aid the United States alone provides to LMICs.¹⁰

These and other challenges to global surgery as a whole also plague the emerging sub-field of global pediatric surgery. Where global surgery may once have been the “neglected stepchild” of global health, global pediatric surgery was the “child not yet born,”¹¹ an area of practice about which even less was known.¹² A vanguard of dedicated pediatric surgeons have propelled the

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rapid growth of this burgeoning field, forming international partnerships and spearheading foundational clinical and research initiatives across the world.¹³ This review article will provide an updated overview of the state of global pediatric surgery, specifically focusing on surgical care for congenital anomalies as a framework in which to discuss the promise of pediatric surgery in reducing the global burden of disease.

A heavy burden to bear: Congenital anomalies in low- and middle-income countries

Congenital anomalies are increasingly recognized as an important global cause of pediatric disease. The human and financial cost of congenital anomalies is particularly acute in LMICs, in which more than 90% of congenital anomalies are estimated to occur.¹⁴ The incidence of congenital anomalies has been estimated at as much as 12 per 1000 live births.¹⁵ However, as we have reported previously, this and other approximations of congenital anomaly incidence and prevalence in LMICs are likely underestimates due to the absence of national congenital anomaly surveillance systems in many LMICs,^{16–18} cultural stigma associated with congenital anomalies, which may impede presentation to healthcare services or even lead to infanticide,^{19,20} and the inherent bias of hospital-based data, which by its nature excludes from estimations of incidence and prevalence those infants with immediately life-threatening conditions who die prior to reaching treatment.^{21,22}

Much of the data from LMICs describes the regional or national burden of congenital disease in terms of mortality. Such data underscores the vast differences in mortality rates between LMICs and high-income countries (HICs).^{18,23} For example, the 30-day mortality rate for infants born with gastroschisis in HICs is 1%²⁴; in LMICs, reported mortality rates range from 14% to 100%.^{24–33} Similarly, in HICs, mortality rates for infants with congenital heart disease range from 3% to 7%³⁴; in LMICs, mortality rates range from 8.8% to 23.5%.^{16,35–38} Such disparities in outcomes arise from a network of factors limiting the availability of timely high quality pediatric surgical services. Many births do not occur in a hospital setting, and families must often travel long distances before reaching care, which can result in additional medical complications.^{26,30,33} Some families may choose to not seek medical care due to the heavy stigma associated with congenital anomalies, as noted above. Even when families present to care centers, they may be unable to access essential pediatric surgical services due to the dire pediatric workforce shortage in many LMICs^{39,40} and the practice limitations that may be imposed by a resource-limited environment, such as decreased availability of life support interventions during and following surgical intervention.^{25,26}

The avertable, long-term burden of disease imposed by treatment delays also poses significant threat to the well-being and security of a child's entire family. Unexpected health crises have been reported to cause high rates of "catastrophic spending" in many LMICs, in which out of pocket healthcare expenses push families into poverty.⁴¹ Families at the lower end of economic ladder are particularly vulnerable to catastrophic spending, as out of pocket medical expenses comprise a larger proportion of familial income.⁴¹ Non-communicable disease in the household has also been related to reduced labor force participation among household members and reduced family income, compounding the economic harms to families caring for children with congenital anomalies.⁴¹

In addition to the costs associated with congenital anomalies described above, data suggests that congenital anomalies contribute significantly to the disease burden in LMICs as described in Disability Adjusted Life Years, or DALYs. DALYs are an established

metric for disease burden; each DALY is equivalent to one year of healthy life lost to premature death or to disability. A recent population-based study in Kenya found that eight prevalent anomalies cause 54–126 DALYs per 1000 children.⁴² Only 3.5% of neonatal surgical need is met in Uganda, resulting in 145, 225 avertable DALYs lost annually due to the six most prevalent anomalies.²⁵ This avertable burden is of comparable magnitude to the DALYs lost per 100,000 population attributable to more traditional targets of health development, such as neglected tropical disease.²⁵ Powerfully, the WHO Global Burden of Disease study identified congenital anomalies as one of the top 20 causes of global morbidity and mortality, accounting for up to 38.8 million DALYs lost annually.² Even this sizable burden may in fact be a gross underestimate of the true disease burden imposed by congenital anomalies, as the impacts of only six congenital anomalies were included in this analysis.⁴³

Coming into its own: Pediatric surgery as an emerging solution to a global problem

A corpus of pioneering work has provided convincing evidence that surgery is both an effective and cost-effective means of dramatically reducing the burden of congenital disease.^{44–50} For example, a recent report from Uganda showed that congenital hydrocephalus can be surgically managed for USD \$59–\$126 per DALY averted.⁵⁰ Similarly, congenital inguinal hernias can be surgically repaired with an estimated incremental cost-effectiveness of USD \$12 per DALY averted.⁵¹ These measures of cost-effectiveness favorably compare to more traditional global public health initiatives, such as the provision of anti-retroviral drugs in sub-Saharan Africa (USD \$350–\$1494 per DALY averted).⁵²

While these individual case studies illustrate that pediatric surgery for select congenital conditions is cost-effective, preliminary evidence also suggests that pediatric surgical wards overall are also an effective and cost-effective means to reducing the substantial burden of congenital disease. A single surgical pediatric ward in Kenya was reported to annually spare 23,169 DALYs, representing on average 22 DALYs spared per surgical procedure.⁴⁷ Pediatric surgical services for congenital and acquired disease cost USD \$44–\$88 USD per DALY spared in a Kenyan refugee camp.⁴⁹ In Cambodia, a pediatric reconstructive surgical ward reported a cost-effectiveness of USD \$99 per DALY averted,⁵³ which, as noted above, compares favorably with other global health interventions.

In line with these pioneering analyses, the true effectiveness and cost-effectiveness of global pediatric surgery must not merely be measured on the level of specific surgeries performed or select congenital conditions treated, but on the systems levels—in other words, the net effect of enhanced and expanded accessibility of high quality pediatric surgical care across disease indications and procedures performed. Additional research in this area is desperately needed to support advocacy for increasing pediatric surgical capacity in LMIC and to inform resource allocation by the global health community.

The next step: Opportunities in global pediatric surgery—for pediatric surgeons

Pediatric surgeons are perfectly positioned to help address the pediatric surgery crisis in LMICs in a variety of ways. In LMICs in which one general pediatric surgeon may be clinically active in the entire country,^{25,54} the immediate provision of surgical care is an important priority. Surgical missions, also known as surgical volunteer trips, represent a popular, well-established mechanism

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