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SURGICAL SYMPOSIUM CONTRIBUTION

Ethics in Global Pediatric Surgery: Existing Dilemmas and Emerging Challenges

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Abstract The rapid growth of global pediatric surgery beyond direct care delivery into research, education, and advocacy necessitates re-evaluation of the traditional ethical paradigms which have governed our partnerships in low- and middle-income countries (LMIC). Within this paper, we consider current and emerging ethical challenges and discuss principles to consider in order to promote autonomous systems for pediatric surgical care in LMIC.

Introduction

The recent evolution of Global Surgery from isolated clinical humanitarian trips toward a comprehensive approach to building surgical capacity in low- and middle-income countries (LMIC) [1] has shifted the ethical landscape. Surgical missions lent themselves easily to traditional ethical models that focused on clinical care [2] (Fig. 1a). However, rapid growth and increasingly diverse avenues of global surgery have afforded little time to reflect on how ethics have been impacted, and whether the overall ethical framework should be re-evaluated in order to match the expanding role of non-clinical work [3] (Fig. 1b). Such deliberation is especially important in global pediatric surgery, given the vulnerable population and the inherent connection to established initiatives in global child health.

This paper examines ethics within four primary domains of capacity-building work in global pediatric surgery: clinical care, education, research, and advocacy. In each section, we will discuss current dilemmas, examine emerging challenges, and suggest possible areas of ethical friction yet to come. This is not meant to be an exhaustive list of ethical considerations, but rather a primer to prompt further discussion.

Clinical care

While well intentioned, the traditional mission approach raised many ethical concerns, including detraction from the livelihood of local providers, local resource consumption, and failure to provide continuous care [1, 4]. In response, high-income country (HIC) approaches have progressed; first to recurrent missions, then long-term and embedded HIC surgeons, and most recently with an increased focus on quality improvement [5]. As children make up almost

Surgical Symposium Contribution: Global Pediatric Surgery: Emerging Progress and Ongoing Challenges.

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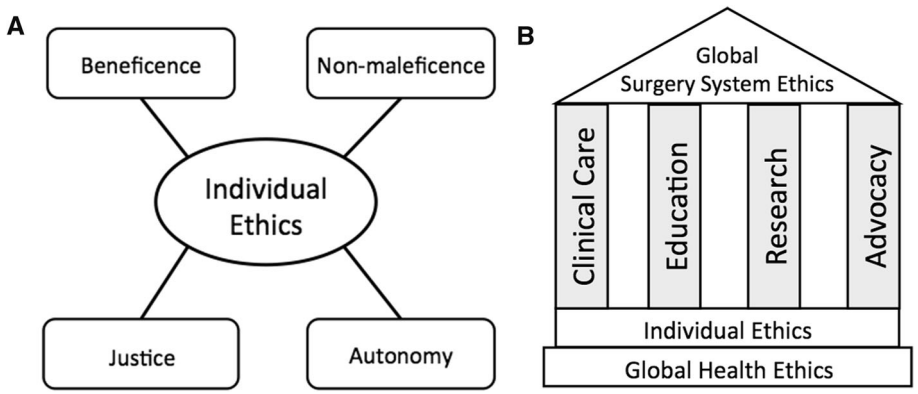

Fig. 1 Evolution of Ethical Considerations in Global Surgery. **a** Traditional ethical paradigms in surgical missions (autonomy, beneficence, non-maleficence, and justice) focused around ensuring ethical care for individual patients. **b** Evolving global surgery ethical paradigms consider the broader global health context with focus on ethical considerations in systems-level education, research and advocacy in addition to clinical care

half the population in LMIC [6], these changes particularly impact global pediatric surgery and raise questions for current and future work.

Existing ethical issues

Appropriateness of direct care delivery

Ensuring the right surgeon performs the right procedure on the right patient with the right resources is fundamental to an ethical approach [7]. Without proper preparation, surgical missions can be plagued by inadequate preoperative evaluation [8], insufficient training to address LMIC pathology [9], and lack of resources to manage complex care [10]. Consider the 4-year-old LMIC child with a new diagnosis of Hirschsprung's. While HIC surgeons may be familiar with pull-through procedures, they are often unfamiliar with very late presentations, enormous colonic size discrepancy, and associated severe malnutrition. Similarly, colostomy in a LMIC may come with burdensome ongoing care needs and social stigma. Potential complications from broadly applying HIC standards in LMIC can be as injurious as no therapy at all. We must consistently re-evaluate the appropriateness of humanitarian care delivered in LMIC, while maintaining a collective focus on longitudinal support and resource utilization. In doing so, all involved ensure that clinical care is ethical and equitable.

Informed consent

Despite a well-understood need for universal informed consent [2], compliance and execution vary [11]. Language, cultural, and ethical barriers [12] have resulted in miscommunication [13], a "hidden pressure" on patients to accept procedures [2], and a general lack of confidence [14]. For example, providing detailed information about treatment, which may be normal in the HIC setting, can be confusing and frightening to parents in LMIC. Parental desperation [15] and cultural differences regarding age of assent [16] represent further pediatric-specific issues. To address these concerns, HIC surgeons should consult with local partners to ensure consent is sensitive to local values, patients are empowered to ask questions, and patient autonomy is maintained. Furthermore, long-term, site-specific engagements can maintain uniformity of such consent processes over time.

Long-term follow-up

A major failing of many isolated, short-term surgical missions is the inability to track an intervention's positive or negative outcomes [17]. Recent guidelines for global pediatric surgical care highlight the importance of advance planning regarding pre-, intra-, and postoperative care, and the implementation of evaluation tools for recurrent missions [9]. Additionally, a few partnerships [18] provide instructive models for ethical short-term LMIC missions, relying upon recurrent trips to create systems for ongoing resource and infrastructure investment. Such capacity-building models address many ethical concerns regarding follow-up care in LMIC [19].

Emerging dilemmas

Subspecialty care

As pediatric surgery and anesthesia capabilities in LMIC become increasingly sophisticated, new considerations arise regarding fair use of resources and ethical decision-making for the individual patient and the overall healthcare system. For instance, with little available LMIC data on survivability by gestational age, the lower age-limit appropriate for intervention can be an ethical challenge.

Specific congenital diseases may also raise challenging ethical issues. Consider gastroschisis, whose survival in HIC depends on parental nutrition (PN) and critical care access. LMIC ability to utilize PN is limited by high up-front costs and untenable waste if PN goes unused [20]. Such costs must be taken in the context that several LMIC studies demonstrate up to a 40% survival without PN [20]. Intuitively, this warrants consideration of the underlying dilemma: in a resource-limited setting, every disease treated means diversion of resources away from another unseen disease.

Quality improvement

Increasingly, LMIC partner with HIC organizations and non-profits for quality improvement (QI), tackling wide-ranging initiatives like outcomes tracking [21], surgical checklists [22], global reporting of perioperative mortality [8, 23], and surgical instrument sterilization [24]. However, a potential risk of such programs is a one-size fits all methodology, wherein HIC partners unwittingly impose familiar QI programs without adequately engaging or empowering local LMIC staff. Despite this, contextually appropriate programs are increasing such as self-styled problem-solving workshops on efficiency in LMIC [25]. As global surgery QI grows, the involvement of local staff through training, project development, and deployment is key to equitability.

New technology

Dissemination of new surgical technology is a source of great opportunity and considerable hazard. This end is best met through introduction of specific products that fill an unmet clinical need and are suitable for the local context [26]. Such a carefully planned approach avoids past pitfalls which paradoxically stifled innovation, exemplified by arbitrary medical device donation, accumulation of unusable equipment [27], and incomplete consideration of operating issues.

Pediatric minimally invasive surgery (MIS) in LMIC represents a potentially broad and exciting technology application that raises new ethical questions [28]. Is unfettered assistance with MIS ethical? Alternatively, is it appropriate to withhold assistance if HIC partners don't believe it can be safely employed? What ethical quandaries exist with telemedicine and remote telesurgery? Given the predominance of MIS in HIC and the history of its development, the consideration of such questions may also be construed as neocolonialist and care must be taken to involve LMIC partners in such discussions.

Education

Education of both HIC and LMIC partners in support of global pediatric surgery is key to creating sustainable, ethical systems of care. In determining best practices for creating optimal educational systems, consideration should be given to existing and emerging ethical paradigms surrounding the appropriate roles for both LMIC and HIC participants.

Existing ethical issues

Role of HIC trainees

Significant enthusiasm exists for student and resident global health electives. However, with high participation rates a number of ethical concerns arise, including the burden HIC trainees place on LMIC hosts [29]. If they go abroad early in their careers, HIC trainees may lack skills to meaningfully participate [30] and can detract from the training of local LMIC trainees [31]. Alternatively, global electives for pediatric surgery fellows are currently not sanctioned by the Accreditation Council for Graduate Medical Education (ACGME), despite pleas from program directors [32]. Regardless of level, HIC trainees should undergo contextual cultural competency education prior to arrival, and the LMIC host must be included in candidate selection and elective organization [30]. Such measures prioritize autonomy of LMIC hosts and help mitigate any harm of adding trainees to a resource-limited setting.

LMIC training—capacity building

The most popular model for training of LMIC providers, especially in trauma, is "train the trainer" courses, where a small team of HIC providers teach LMIC counterparts with the goal that these techniques are passed on [33]. However, the potential benefit varies, due to disparity in type and nature of these courses, reliance on HIC volunteers, and limitations in the amount of material covered [34]. Future implementation will benefit from increased LMIC governance and development of curricula with greater depth and broader coverage of local pediatric surgical conditions.

Another approach to capacity building is "twinning," which consists of bi-directional exchanges between HIC and LMIC faculty or trainees, whereby both groups spend equal amounts of time in each setting [35]. When successful, these partnerships can expose HIC and LMIC fellows to different surgical conditions and increase cost consciousness among HIC participants [36]. However, these are not true "exchanges" if LMIC trainees are unable

to have an active role in HIC care. The primary barrier is typically licensure limits on LMIC individuals which restrict participation to observation [35]. However, rather than relying on clinical observation alone, HIC partners could provide meaningful alternatives to ensure reciprocity and equity, such as operative simulation, basic research methodology coursework, or focused education on diseases that are often fatal in LMIC.

Brain drain

In training LMIC surgeons and staff, many have raised ethical concerns about "brain drain," whereby highly trained LMIC individuals emigrate to HIC [37]. In order to prevent such migration, a number of programs have implemented restrictions compelling LMIC participants to return to their home countries [38]. However, concern for systemic mal-distribution of surgeons worldwide, must be counterbalanced against the need to respect the individual liberty, autonomy, and human rights of LMIC individuals. There is also abundant literature on in-country efforts that can stem the tide of migration, including mitigating LMIC surgeon burnout [39, 40]. These issues are especially salient in pediatric surgery due to the huge scarcity of surgeons and even more limited infrastructure.

Emerging dilemmas

Creating education systems for pediatric surgical care

In some cases, training programs in LMIC often rely heavily on HIC surgeons because there are so few local, surgical sub-specialists [41]. While well intentioned, these HIC-dependent residencies run the risk of sudden collapse with the possible loss of HIC resources. As we transition educational approaches, it is unhealthy for LMIC programs to depend entirely on embedded HIC collaborators. Instead, there should be steady effort to build education capacity while engaging local providers in program creation, transitioning authority to them as early as possible, and creating customizable initiatives specific to individual country shortages where needed.

The African Pediatric Fellowship Program provides a coordinated, regionally driven approach to building LMIC pediatric provider capacity. Centered at Red Cross War Memorial Children's Hospital in Cape Town, this program brings trainees from other African countries to South Africa for 2.5 years with the aim of building capacity in a pre-identified area of need. Most notably, this program works with fellows to ensure training is relevant to home-country conditions, needs and resources, and provides them with research and leadership instruction, further empowering them to become change agents [38]. Since 2008, this program trained 60 fellows, including 6 pediatric surgeons, 1 neurosurgeon, 2 anesthesiologists, and 3 intensivists, with many returning fellows becoming the first subspecialist in their country. Though more work-intensive, this creates an educational system that can bolster surgical capacity in an ethically sound manner.

Developing infrastructure for academic surgery

Because of the rare diseases and highly specialized knowledge and skills of pediatric surgery, research and education training in LMIC is critical. To help avoid permanent dependency on HIC, develop autonomous, well-functioning academic systems, and create a pipeline to improve long-term workforce capacity, local faculty must develop skills to continue such initiatives. The West African College of Surgeons (WACS) and Association for Academic Surgery's (AAS) joint effort to deploy the Fundamentals of Surgical Research course (FSRC) in West Africa (WACS/AAS FSRC), demonstrates a model for educating local providers in skills necessary to conduct research [42]. Importantly, this program was successful in transitioning administration to local partners. In doing so, the course not only ensured training of future surgeons, but also allowed the program to triple the number of trainees, while cutting costs [43]. Overall, increasing academic surgical capacity will take time and will require universities, governments, funding agencies, and other institutions to partner in an ethically conscious manner that promotes local sustainability.

Training the HIC surgeon

Lastly, as global surgery expands, those involved should consider what individual skills, in addition to clinical expertise, are needed to meaningfully improve global surgical care [44]. Opportunities exist to gain degrees in public health, education, or public policy [45]. Such training can help HIC surgeons ensure initiatives are high quality, reproducible, evidence-based, and maximally beneficial. Additionally, as such training affords learning from the much longer experience of non-surgical, public health colleagues, global surgeons can utilize their best practices as well. Overall, by gaining additional skills, HIC actors can avoid ethical pitfalls while ensuring their contributions are based in an area of expertise.

Research

Research collaborations and a common research agenda for global pediatric surgery are critical to a sustainable, functional healthcare system [46] as it provides the evidence

from which care is directed. Recent, rapid expansion of research comes with the need to explore contemporaneous ethical dilemmas, and the opportunity to learn from global health colleagues who have a rich history of investigation in LMIC.

Existing ethical issues

Conduct of research in LMIC

Underutilization of local collaboration in global surgical research efforts results in poor data fidelity [47], resource misallocation [48], and potential exploitation [49]. This is often apparent in inequitable distribution of authorship [50]. Notably, one study of Ugandan trainees demonstrated that despite 28% reporting collaborative research participation, none were published co-authors [48]. Through early inclusion of LMIC collaborators in all components of the research process—including creation of collaborative outcome databases, data analysis, publication, and building research capacity—HIC collaborators can facilitate effective research system growth without directing all efforts.

There is much debate around research involving LMIC individuals including children, notably in areas of informed consent [47], and defining a standard by which to compare experimental interventions [49]. Placebo or sham surgery is an effective method of comparison, as noted by non-surgical, global health colleagues, but care must be taken to thoroughly explain its purpose and necessity as these procedures can otherwise be construed as exploitative [51]. Even without a placebo, it can be difficult to determine the appropriate medical standard or comparison group for research, resulting in ethical tension from balancing the idealized HIC standard against local practice. It is not appropriate, for instance, to compare outcomes of a study to improve gastroschisis care in Uganda, which has a 98% mortality rate [52], to that of one in HIC, where care includes PN and complex spring-loaded silos. Alternatively, a study grounded to the local standard ensures results are generalizable to indigenous conditions (equipment, medications, and practitioners), impact is maximized, and a balance is struck favoring effective research over uninformed experimentation.

Emerging dilemmas

Funding

An unintended ethical consequence of HIC-driven research funding has been over-support of initiatives according to HIC sociocultural priorities. A stark example is the substantial funding of communicable diseases like HIV/AIDS in LMIC children, while injury carries greater disease burden but remains underfunded [53]. To promote the economic necessity of global surgical research, an emphasis must be placed on development of loco-regional resources in carefully constructed partnerships with HIC. The promotion of strategic, data-driven, national surgical plans by the Global Initiative for Children's Surgery (GICS) provides one such avenue for future equitable funding of research [54].

Building research infrastructure

Research collaboratives are emerging as a popular attempt to increase LMIC investigative capacity [6, 18]. Despite obvious benefits, these relationships can indirectly promote a system of research dependency, whereby all scientific or specimen analysis occurs in the HIC [55]. Regardless of meaningful conclusions, this research cannot be ultimately sustained without development of LMIC research infrastructure [56]. While it may delay completion of individual projects, the global surgeon should simultaneously assist expansion of locally based, essential technical knowledge and research systems wherever possible.

Creation of sustainable research requires investment in laboratory space, statistical support, and protected time for LMIC surgeons [50]. The Training Health Researchers into Vocational Excellence in East Africa (THRiVE) [57] initiative supports LMIC research facilities, collaboratively trained physician-scientists and development of ancillary research resources in an effort to build research infrastructure. Growth of research architecture provides a unique opportunity for HIC surgeons to engage in a limited, capacity-building intervention, targeting skills LMIC scientists want to develop, with the goal of producing self-sufficient systems that function after initial funding ends.

In creating research systems, more numerous and comprehensive LMIC ethical review boards are required [58]. Despite ongoing human research in LMIC, up to 36% of the World Health Organization (WHO) African Region States report an absence or under-resourcing of ethics committees [59]. Rational design of LMIC research infrastructure must include development of locally controlled and funded ethical review boards prior to initiation of research. The global surgeon is uniquely poised to facilitate this ethical imperative in a way that prioritizes LMIC collaborators in their creation.

Advocacy

Advocacy lies at the heart of global pediatric surgery, but organized work in the area is only emerging. As such, it raises a range of ethical dilemmas. An ethical advocate must have a strong foundation in the community's

priorities and capabilities, while understanding the basic healthcare structure. When advocating for care improvements, one must understand why current limitations exist, what resources are required to improve care, and what aspects of care may suffer if resources are diverted. This requires that the advocate not only have a vision for change, but how to elevate the entire system rather than just one component.

Individual & institutional advocacy

Priority setting

The process of priority setting should be data driven and involve LMIC partners. Humanitarian work has historically advocated for diseases that HIC actors found most compelling [13], like cleft lip/palate deformities [60]. However, other unseen diseases, like imperforate anus, garnered little attention, despite similar disease burden [61]. Accurate data, and reliance on measures such as the disability adjusted life years (DALYs) index, are essential to development of a rational, fair approach to advocacy. Priorities for intervention, if not sourced from data, may be derived from the funder's cultural preferences.

Methods of advocacy and engagement

As with the previously discussed domains, a primary challenge in advocacy is inherent power imbalance. Too frequently, HIC-LMIC exchanges can create systems that rely on HIC involvement [56]. Global surgery advocates must carefully consider the entire process and create mutually agreed upon plans for both initiation and withdrawal of HIC-based support prior to deploying new solutions, ideas, and programs.

The relationship between the Royal College of Surgeons in Ireland (RCSI) and the College of Surgeons of East, Central, and Southern Africa (COSECSA) provides an example of a potentially fruitful HIC-LMIC partnership. RCSI has been instrumental in developing COSECSA's training program, conducting courses for COSECSA surgeons, and played a key role in benchmarking examination [62]. Given the progress made in training LMIC surgeons, there may soon be sufficient local capacity for LMIC partners to assume RCSI's roles. Therein, as LMIC capacity grows, each partner's role should be continuously re-evaluated, while enacting plans for gradual uncoupling.

Additionally, HIC advocates should consider their level of engagement in LMIC systems. Historically, many advocates took the initial step of connecting with ministries of health and LMIC governments to lobby for surgical issues. With time, this led to some HIC partners being invited to draft laws governing systems for injury, surgical care, or the development of national surgical plans [63]. Yet, this is a potential slippery slope toward LMIC governmental reliance on HIC advocates over local providers, depriving them of autonomy and self-governance. To avoid this dilemma, HIC partners must promote the role of local providers to LMIC governments, while planning for their own eventual obsolescence.

System-level advocacy

Developing a global agenda for health intervention

The global health agenda has traditionally not included global surgery, much less pediatric surgery. However, evidence-based development goals that include surgical care are emerging [64]. The consensus indicators of access, quality, financial risk protection, and monitoring represent necessary tools to develop equitable surgical systems around the globe. Additionally, GICS has brought advocacy for pediatric surgery to the global stage and provides guidance around priorities for improving children's surgical care worldwide [63]. As overall advocacy efforts grow we will need to continuously re-evaluate the ethics of our processes, from distribution of funds and resources, to appropriate scaling of interventions, and balance between HIC and LMIC involvement.

Conclusion

Global pediatric surgery's transition from humanitarian trips to comprehensive healthcare building has created difficult to recognize but powerful ethical dilemmas (Table 1). Great consideration must be given for deliberate planning of both initiation of work with LMIC partners, and also eventual surrender of program leadership to them. With systematic expansion in education and research, it is imperative to identify methods of building scientific infrastructure while

Table 1 Key points: ethical considerations for systems-level global pediatric surgery

- Create mutually agreeable exit (transition) plans prior to even commencing a partnership
- Engage with LMIC partners rather than embedding within their system
- Consciously aim to develop autonomous, not dependent LMIC systems of surgical care
- Learn from global, non-surgical, health examples when exploring solutions to current or potential ethical dilemmas
- Continuously re-evaluate ethical implications of individual and collective global surgery work

working toward creation of autonomous systems. HIC initiatives should avoid embedding within existing systems, and instead place LMIC surgeons at the center of systems improvement. Finally, as rapid progress ensues, we must continually reconsider the ethical implications of our interventions. Only by doing so can we truly begin the process of pediatric surgical capacity building on a global scale.

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Compliance with ethical standards

Conflict of interest All authors have declared that they have no conflicts of interest.

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