Ethical considerations in targeted paediatric neurosurgery missions

Samuel A Hughes, Rahul Jandial

ABSTRACT

Within the context of global health development approaches, surgical missions to provide care for underserved populations remain the least studied interventions with regard to their methodology. Because of the unique logistical needs of delivering operative care, surgical missions are often described solely in terms of cases performed, with a paucity of discourse on medical ethics. Within surgery, subspecialties that serve patients on a non-elective basis should, it could be argued, create mission strategies that involve a didactic approach and the propagation of sustainable surgical care. The ethical considerations have yet to be described for paediatric neurosurgical outreach missions. We present here the perspectives of neurosurgeons who have participated in surgical outreach missions in Central America, South America, Eastern Europe and sub-Saharan Africa from the vantage point of both the visiting mission team and the host team that accommodates the mission efforts.

INTRODUCTION

Awareness of global health-defined as study, research, and practice that prioritizes improving health equity for all people—is an increasing focus of political organizations, governmental bodies, and American medical education. Various models of medical outreach have demonstrated the ability to create sustainable change through education and immunisation for disease prevention, improved treatment of infection and by water purification.

Surgical outreach missions also deliver care that benefits citizens of the host country, but because of the sophistication of skills and equipment needed, the impact is often episodic rather than sustainable.

It would seem that ethical considerations would have played a role at best when surgeons visit underdeveloped nations to provide care not available in the host country. This is an oversimplification because medical and surgical missions are never ethically neutral. Indeed, on the one hand, outreach teams are motivated by ‘good will’, but, on the other, underlying the execution of surgical outreach missions are layers of complicated motives and benefits, which can confound the original intention of simply ‘doing good’.

Historical appraisal of medical research provides an example of how good intentions can be complex. The cost advantages and ease of enrolling patients in underdeveloped nations have led to inclusion of international patients in numerous clinical trials. This inclusion represented a paradigm shift in the way research was perceived and performed internationally. Initially, physicians viewed treating patients in underdeveloped nations as an entirely benevolent enterprise, but later evaluation revealed that this complex process required the same structural protections afforded to patients undergoing clinical trials in the USA or Europe. We anticipate that in time lessons gleaned from international clinical trials, which are reported in numerous publications, will reveal a new path for international medical missions to follow.

Physicians performing one of the most challenging surgical enterprises, neurological surgery, have also participated in international surgical outreach. Based on our experiences in these types of missions in Central America, South America, Eastern Europe and sub-Saharan Africa, we offer perspectives to ethical considerations of both teams involved.

This topic—particularly insights derived from surgical missions—is not often reported in the literature.

ETHICAL CONSIDERATIONS RELATED TO THE VISITING MISSION TEAM

Over the last few decades, surgical outreach missions have increased in scope, primarily in the care of cleft lip and palate deformities and in reconstructive surgery. In parallel, expanding digital technology has allowed abundant insight into the financial and marketing mechanisms underlying mission execution. The following concerns could pose conflicts and should be considered ethical elements in the growing field of targeted international surgical missions.

Self-serving aspects

It is anathema, both in the general population and among surgeons, to suggest that clinicians are motivated by anything other than good will when conceiving, pursuing and performing surgical missions. By definition, surgeons are not remunerated for their efforts, and many use personal leave or vacation time to pursue benevolent activities to care for the global health community. Medicine and surgery are international skills and in many ways represent the very best interracial, intercultural and interreligious collaboration for improving the health of humanity (box 1). Nonetheless, there are clearly benefits for the visiting mission team. It is not uncommon at the mission’s completion for visitors to state that ‘we have learned or benefitted as much if not more than the people we helped’.

In addition to personal fulfilment, there are benefits not previously described in the literature that are amplified in the digital information age. First, medical universities and institutions inevitably publicise missions by members of their faculty and
The need for and use of informed consent is highly variable between different socioeconomic and geopolitical landscapes visited by surgical missions. Reports of successful international clinical trials indicate that informed consent can be effectively implemented in numerous healthcare scenarios and settings. Often surgical outreach requires a research component: it may be necessary to identify health needs to be met during a short-term intervention, assess effectiveness of those interventions and monitor long-term health gain. Currently, there is no published research demonstrating the use of advanced directives, informed consents or institutional review boards during short-term volunteerism either in medical or surgical missions. It is imperative that we not overlook the capacity of medically underserved populations to participate in fundamental elements of informing and consenting. This opinion is shared by the European Commission’s directive, ‘Ethics in research and international cooperation’ cogently articulated as the following: ‘Independent of the cultural particularities that may require a slight modification of the standard procedures, the principle of Informed Consent — individual, comprehensible and fully documented — is fundamental. It must be adhered to in all circumstances without exposing the individual to discrimination or danger simply because the procedure does not fully comply with the local cultural settings. It is also important to ensure that the participants will not face any risk that relates to their refusal to participate in the planned study, and are offered actual alternative options.’ It is important that citizens embrace the idea that, even when options are limited, their consent is fundamental to the process and they are the drivers of their medical care.

**ETHICAL CONSIDERATIONS RELATED TO THE HOST TEAM**

Just as visiting teams in short-term surgical outreach missions must recognise ethical considerations, potential conflicts of interest also exist for the host teams.

**Conflicts of interest**

Healthcare workers and physicians who dedicate their lives or a portion of their work week to care for underserved populations in their resident country seldom exhibit ulterior motives in providing this care. Given the limited resources and competitive environment of developing a private practice, many doctors in America do not participate in the care of the underserved. The most common scenario that we have encountered in delivery of care to the poor in a host country is an academic surgeon who may work part of the week in a ‘government’ hospital and the remainder in a ‘private’ clinic. In this scenario, there exists an ethical hazard that the host team will use donated equipment and skills to benefit their private practices and not for the intended mission goals, namely, to benefit the underserved of the host country. There are, indeed, anecdotal reports of donated equipment being moved to private clinics after completion of targeted missions. The risk of this form of misappropriation, we feel, is minimised by repeated personal visits by mission members and diligent follow-up with the host team. If newly acquired operative skills (ie, those inculcated by the mission team’s didactic outreach) lead to improvement in the ‘private’ element of a surgeon’s practice, this in itself is not a conflict. Relocation of equipment intended for charity hospitals to private clinics is, however, unacceptable. Ultimately, the depth of dedication and commitment to the underserved is one
that should be closely evaluated by inperson site evaluations by auditors prior to initiation of full-scale missions.

Futile and/or compromised care
Host teams usually have significantly limited resources. And, since most missions are charitable endeavours, discussion of optimal use of finite funds is necessary. However, integrating financial common sense with cost–benefit analysis of human life is a calculus not easily performed. Therein lies a major ethical consideration that applies to all members of the host and visiting teams. Both teams should have an understanding about the effective use of mission resources. Care should be appropriate to the needs of the community and not divert local resources inappropriately. No algorithmic approach can be devised to accomplish this since the healthcare ecosystem in each region is unique. Some basic principles can be stated but need to be personalised to each unique medical outreach context (Box 2).

The desire for a ‘successful’ mission may create an environment where both the visiting and hosting teams feel pressed to demonstrate that a certain minimal number of operative cases can be performed. Indeed, for charitable organisations sponsoring the trips, the number of patients treated may be a component of their organisational fundraising strategies. Ultimately, these decisions lie with the surgeons involved and often significant teaching and logistical elements can be established leading to success in some of the varied didactic objectives within each mission. Case volume is not the only determinant of success. Poorly planned large volume missions may be expected in some part based on the population that was served in a developing country, it does introduce potential risk in declaring whether efforts were truly successful or not. Accordingly, the ‘success’ of surgical missions should be declared with caution and only after diligence.

Similarly, operative cases should be selected to be performed that are compatible with the resources possessed by patients to provide necessary postoperative care. For example, pituitary surgery that may leave the patient with panhypopituitarism postoperatively (whose treatment would require lifelong medication, the lack of which could lead to the patient’s death) is not appropriate in a host country where such medications are not readily available. Poor health and advanced disease increase the risks and decrease potential benefits of some interventions, and one cannot assume that the outcomes of interventions in developing countries are identical to outcomes of the same intervention in developed countries. Thus, for example, in one case, described by Dupuis, two malnourished children died after cleft palate operations performed by medical volunteers from postoperative complications related to nutritional deficiencies. Thus, peri-operative evaluation and management are a critical element of surgical mission design and operative case selection.

CONCLUSIONS
We have considered ethical issues relevant to a targeted model of international surgical outreach and propose that clinicians could benefit from our experience and analysis. First, we use site evaluation to establish rapport, evaluate potential hidden agendas and study the local healthcare ecosystem. Diligence in this initial step is paramount because, in our experience, the site’s capacity for preoperative evaluation and care, post-operative management, and retention of donated resources can be difficult for host teams to evaluate accurately. In the case of our surgical team, some sites have undergone ‘site evaluation’ and, unfortunately, been found inappropriate for proposed missions due to an incompatibility of mission resources and the proposed sites’ ‘ecosystems’. If targeted missions are considered valuable and feasible based on a site evaluation, we execute missions with a frugality that is a required sensibility when one visits underserved areas of the world. We have not directly participated in obtaining informed consent from patients, but have made that a requirement for host sites so that patient involvement is ensured. Thus far, we feel that this procedure has not been executed to the standards used in America, and it remains a priority for future missions. Part of the process of working with host surgeons is to ensure that there is a clear discussion about the ability of the patient or patient’s family to secure necessary postoperative medicines, follow-up and reoperation, if necessary. Medical volunteers may also need to make decisions about whom to treat when there are more patients in need than the available resources. Ultimately, the consideration of ethics and conflicts of interest should be embraced so that teams involved in surgical missions can fulfil shared philanthropic objectives, both in ethos and in practice.

Contributors RJ and SH have contributed equally to this manuscript.

Competing interests RJ is a scholar of the City of Hope institutional NIH K12 grant.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

Box 2: Seven guiding principles in outlining a model for sustainable short-term international medical trips

1. Mission: by establishing a common sense of purpose
2. Collaboration: with the community and its infrastructure
3. Education: for the community and volunteers
4. Service: of the community’s health needs
5. Teamwork: among team members of diverse specialties
6. Sustainability: by working to build capacity in the local community
7. Evaluation: of outcomes and whether goals are being met