

Challenges and opportunities for effective data collection in global neurosurgery: traumatic brain injury surveillance experience in Malawi

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Global health research can transform clinical and surgical practice worldwide. Partnerships between US academic centers and hospitals in low- and middle-income countries can improve clinical care at the host institution hospital and give the visiting institution access to a large volume of valuable research data. Recognizing the value of these partnerships, the University of North Carolina (UNC) formed a partnership with Kamuzu Central Hospital (KCH) in Lilongwe, Malawi.

The Department of Neurosurgery joined the partnership with KCH and designed a Head Trauma Surveillance Registry. The success of this registry depended on the development of methods to accurately collect head injury data at KCH. Since medical record documentation is often unreliable in this setting, data collection teams were implemented to capture data from head trauma patients on a 24-hours-a-day, 7-days-a-week basis. As data collection improved, pilot groups tested methods to collect new variables and the registry expanded. UNC provided onsite and remote oversight to strengthen the accuracy of the data.

Data accuracy still remains a hurdle in global research. Data collection teams, oversight from UNC, pilot group testing, and meaningful collaboration with local physicians improved the accuracy of the head trauma registry. Overall, these methods helped create a more accurate epidemiological and outcomes-centered analysis of brain injury patients at KCH to date.

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COLLABORATIVE efforts in global neurosurgery can generate important discoveries, which can influence clinical and surgical practice in high-, low-, and middle-income countries. At many low-income neurosurgery sites or resource-poor environments, inconsistent access to health interventions and high clinical volume of complications not frequently seen in high- and middle-income countries, drive researchers to propose alternative monitoring and therapeutic techniques. The data collection and research output brings innovation and valuable insight that would otherwise not exist in neurosurgical literature. For example, research designed and conducted in Uganda resulted in development of the endoscopic third ventriculostomy (ETV) and bilateral choroid plexus cauterization (CPC) technique (ETV/CPC) to treat infants with hydrocephalus.⁸ About a quarter of the 400,000 global cases of hydrocephalus occur in this resource-poor region.⁹ This high clinical volume drove development of a low-cost

treatment, which is now used in the United States to treat infants with hydrocephalus. Similarly, research designed in Bolivia and Ecuador resulted in a randomized clinical trial comparing invasive intracranial pressure monitoring to imaging and serial clinical examinations in the management of traumatic brain injury (TBI). This trial failed to demonstrate the superiority of invasive intracranial pressure monitoring, which, in the absence of outcomes data, has generally been accepted as standard of care in the US.¹ For this reason, a randomized trial of this design would not have been approved in the US. High-quality data collection was critical to drawing conclusions in these studies, although little is known about the obstacles and solutions to obtaining high-quality data.

Recognizing the importance of global research, the University of North Carolina (UNC) developed a collaborative relationship with the Ministry of Health in Malawi in 1999 to study infectious disease at Kamuzu Central Hos-

ABBREVIATIONS GCS = Glasgow Coma Scale; KCH = Kamuzu Central Hospital; LMICs = low- and middle-income countries; TBI = traumatic brain injury; UNC = University of North Carolina.

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TABLE 1. UNC departments collaborating with KCH

UNC Department	Year Partnership Established
Infectious Disease	1999
General Surgery	2008
Pediatrics	2013
Obstetrics & Gynecology	2013
Anesthesiology	2015
Neurosurgery	2016
Urology	2016
Psychiatry	2016

pital (KCH) in Lilongwe, Malawi. This partnership has expanded to include more departments from UNC and has led to valuable global surgical research.

For this partnership with Malawi to be transformative for global neurosurgery research, we must address the unique challenges of conducting research in low- and middle-income countries (LMICs). In LMICs, overwhelming clinical volume relegates research priority. Additionally, the absence of electronic medical records and the poor or absent documentation within paper charting stalls many research efforts. Without consistent documentation, retrospective data collection becomes futile and necessitates real-time data collection personnel. For these reasons, our surgical teams focused on data collection early in our partnership, and have adapted methods over time. We have developed and maintained an accurate Head Trauma Surveillance Registry allowing for research, recognizing the clinical areas of concern and changing clinical practices. Despite the challenges of research in LMICs, the UNC Departments of Surgery and Neurosurgery have worked to cultivate strategic partnerships and develop a model of data collection in LMICs to further global neurosurgical research.

Evolution of the UNC Research Experience in Malawi

Strategic Partnerships

In 1999, UNC began a collaborative relationship with the Ministry of Health in Malawi to study infectious diseases at KCH. The partnership has expanded to include other UNC departments (Table 1). Although we are early in our combined global experience, the UNC Departments of Surgery and Neurosurgery modeled our global program after previously successful global partnerships in sub-Saharan Africa, as well as the already successful infectious diseases work at KCH. These successful partnerships serve both to provide clinical benefit to the host institution and to support the research efforts of visiting institutions. The UNC Department of Surgery strengthened the surgical research partnership by establishing a general surgery residency training program to train Malawians. This training program and oversight by UNC faculty members allows KCH to immediately treat more of the large volume of patients who need care. It also increases the number of physicians trained locally, which, in turn, increases the likelihood that these physicians will stay and continue to work in Malawi and alleviate the overwhelming clinical

volume. The large volume of patients affords UNC access to a very large dataset. Our group focused data collection on traumatic brain injury (TBI) because it is a major cause of morbidity and mortality in Malawi.

The key to our success is forging a collaborative partnership not just between our institutions (UNC and KCH) but with the Malawian Ministry of Health. With each new initiative, we deliberate with the ministry to ensure that our plans align with the larger health care strategic goals of the country. On occasion, we assist in providing the data to inform health policy and strategic clinical and public health direction. However, the rate of change in personnel within the ministry is high, resulting in a lack of continuity of vision. Therefore, building new relationships and justifying existing collaborations and vision may be time consuming.

Registry Development

In 2008, after obtaining IRB approval, the UNC Department of Surgery began a trauma registry, which included head injury data pertinent to neurosurgery. Variables collected relevant to the characterization of head injury include baseline demographics, injury mechanism, transfer status, disposition from the emergency room, admission status, admission vital signs, mortality, and Glasgow Coma Scale (GCS) score. While this collection began with simple demographics, additional variables were added as data collection methods improved.

Data Collection Team Development

Retrospective data collection can be useful in many US hospital environments; however, the absence of reliable medical record documentation in many LMICs can make this unrealistic. UNC established data collection teams to enroll trauma patients into the registry at the time of their initial evaluations. Each data collection team consisted of 4 Malawian high school graduates hired as data clerks. The schedules were arranged to allow for data collection coverage 24 hours a day, 7 days a week. Since Malawi lacks enough clinical nursing care, including research nursing staff was not practical.

When the number of data collection variables and patients included in the registry increased, 2 more data clerks were added to the team. The data collection team was integrated into the clinical flow, which allowed the data clerks to obtain vital signs and patient information, capture the details of trauma at presentation, and follow patients through their hospital stay to gather outcome data. These data were advantageous to both clinical care and research efforts as the clerks became integrated into the trauma bay workflow.

Pilot Groups

Capture of a large volume of data may sometimes compensate for missing data; however, missing data may not be truly random and omissions may occur for logistical reasons. We found that validating collection with a pilot group uncovered educational or logistical issues. We then addressed logistical roadblocks before formal study data collection. This was done for each subset or addition of

new variables added to the database. Pilot groups consisted of data clerks, UNC residents, and UNC medical students. UNC residents and medical students worked side-by-side with the data clerks to explain the new variables being collected and develop accurate collection methods.

Addition of Outcomes Data

Within the 1st year of data collection, outcome data on head trauma patients were added to the registry. To collect these data, data clerks followed patients throughout their hospital stay. Outcome data such as neurological examination findings, radiographic data, and functional outcomes were recorded in the registry.

Addition of Morgue Data

Traumatic brain injury also accounted for a high number of pre-hospital deaths. Without these data, the registry under-represented the true burden of TBI-related deaths. In 2014, we began to include all trauma patients who were dead on arrival to KCH. A post-mortem clinical examination was performed to assess the anatomical location of injury and deduce the likely cause of death.

Addition of Transportation and Road Safety Database Information

Traumatic brain injury as a result of motor vehicle accidents accounts for an unknown number of pre-hospital deaths and deaths never reported to KCH. In order to create a more comprehensive look at traumatic injury in Malawi, we began to incorporate data from the Malawian National Road Safety Database in 2015. This captured all motor vehicle traffic collisions, scene deaths, and injuries.

Oversight

Several layers of oversight and data maintenance were necessary. Surgery residents and medical students traveled to Malawi for extended periods of time (1–2 years) to monitor the accuracy of general data and specific interest level data. If these data were missing or inconsistent, residents and medical students would re-educate the global site research team, while also providing clinical support for the hospital. Residents provided the most consistent on-the-ground support for the head injury database without lapses in presence and oversight.

UNC faculty members typically visit the site 4 times per year for several weeks at a time to provide general oversight to the projects. We also implemented remote, real-time surveillance by principal investigators to identify missing or inconsistent data. This meant data collection required regular remote evaluation by faculty to spot discrepancies, consistently missing data, or other data irregularities. This would then be communicated to residents and students on the ground in Malawi to re-educate and improve data consistency and accuracy.

Results and Discussion

The establishment of a trusting partnership allowed us to develop a data collection model to increase the accuracy of the head trauma registry. Without support from the host institution we would not have been able to incorporate data clerks into the clinic flow. As staff understood

the role of data clerks better, data collection improved and the trauma registry became more robust as evidenced by the increase in data volume over the years, not simply attributable to changes in population or hospital structure. The volume of patients included in the registry increased from 6,000 in the 1st year to 12,000 and 15,000 in the 2nd and 3rd years, respectively. Instituting this data collection team created the most accurate epidemiological look at trauma patients presenting at KCH.

Although the volume and quality of data collected increased, data inaccuracy still existed throughout the registry. Many factors contributed to data inaccuracy, including the compensation of data clerks. Data clerk salary levels became a constant roadblock to increasing the number of variables or data collection. The Malawian currency, the Kwacha, devalues quickly, so data clerk compensation needs to be updated frequently. If the salaries of data clerks were not increased when a new variable was collected, we observed study neglect or data inaccuracy. We attempted to increase the number of cases captured through per patient incentives for clerks, but this also resulted in inaccurate data.

Data inaccuracy also occurred when we expected data clerks to obtain GCS scores, operative details, imaging information, and complicated outcomes data. These expectations were not realistic, as an understanding of these complex data requires a higher level of education. We have found that the addition of a point person from the clinical team—such as a local surgical resident with a vested interest in the research who can consult with the data clerks and provide ongoing education and data audits—increases data accuracy. Similar models have been successful in other sub-Saharan data collection efforts, which emphasizes the importance of rigorous training and participation from the host institution. This fosters a sense of ownership from both institutions and places a value on persons collecting data.^{5,6}

Data accuracy also increased with remote, real-time surveillance of the principal investigating surgeon to identify missing or inconsistent data and quickly implement changes when needed. In an effort to increase data accuracy and further characterize TBI in our setting, a 4th-year medical student expanded data collection to include neurological examination findings, radiographic data, and functional outcomes. The medical student also directly supervised data collection to ensure that outcomes and other data parameters were recorded correctly and consistently. These 9 months of medical student oversight increased the quality of the data capture, as it provided constant supervision from the country sponsoring the research. As a result, these data were meaningful and publishable.² In the subsequent absence of this oversight, data fidelity and completeness again diminished. This experience highlights the importance of having a consistent point person at the global site from the country sponsoring the research. More consistent medical student coverage, with handoffs, is being considered for the future continuation of our research.

UNC's other collaborative projects with a neurosurgical focus also highlight challenges and potential solutions of global research. While our collection methods may provide solutions for providers with similar challenges,

we also rely on local physicians for meaningful data collection.⁴ For example, we published a retrospective study, using data made available by a local neurosurgeon, to evaluate the effectiveness of exploratory burr holes in the reduction of mortality in patients with severe traumatic brain injury and localizing signs when CT scanners were unavailable.^{3,7} These data were accessible because the local neurosurgeon kept separate records of her own, making the data more complete than normal Malawian hospital records. However, as we highlighted in the publication, the discordant nature of the UNC trauma database used to gather a control group of patients with severe TBI allowed for an imperfect comparison, at best, which may have affected our analysis.

As academic institutions contemplate embarking on a global neurosurgery agenda, identifying funding streams to make this feasible and sustainable is key. The use of clinical revenue for global surgery is ill-advised and will usually be met with resistance from most surgical chairs. The first type of departmental funding is usually in the form of faculty time. Beyond that, we have succeeded mostly by embracing philanthropy. Identifying donors who share our passion for global health has been invaluable. These individuals recognize the potential benefits of our work, not just for our partners in the resource-poor country, but for the potential knowledge that we may glean that may benefit us in the United States. Furthermore, partnering with larger multinational companies within the health care sector is encouraged. Lastly, for an academic medical center, adding new knowledge through innovative research requires grant funding. Encouraging faculty members to seek global health grant funding is crucial.

Cultivating a trusting partnership between the US research institution and the global site remains the key to successful global research. Global surgery attracts many faculty members, residents, and students, but a revolving-door approach with new faces frequently creates a transient presence and strains the collaboration. These relationships take time to build and require dedication to a single global site. Infrequent trips or short trips from the US research institution team makes building these relationships difficult and breaks the momentum of both the clinical and research teams. Not all residents and medical students interested in global surgery possess cultural sensitivity, and the lack of that sensitivity can threaten these relationships. Trainees exhibiting a colonial attitude may compromise the bidirectional global partnership and they must be extracted from the environment immediately.

Conclusions

In summary, the partnership in neurosurgery between a US institution and a global site can be remarkably beneficial to both, but it requires dedication, patience, and acknowledgment of an invaluable, yet fragile cooperation. Central to this collaboration is the understanding that the relationship must be designed to be mutually beneficial. This relationship often provides the visiting US institution with access to a rich and previously untapped study population, but it is important to identify some tangible benefit for the host institution, such as additional clinical services or clinical

education/training. As collaboration in global surgery has potential to change care across the world, we will continue to carefully cultivate our valuable global partnerships and offer our experience to aid other currently existing or yet-to-be-established global neurosurgery programs.

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Disclosures

The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

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Conception and design: Quinsey, Charles, Hadar. Acquisition of data: Quinsey, Eaton, Northam, Charles, Hadar. Analysis and interpretation of data: Quinsey, Eaton, Northam, Charles, Hadar. Drafting the article: all authors. Critically revising the article: all authors. Reviewed submitted version of manuscript: all authors. Approved the final version of the manuscript on behalf of all authors: Quinsey.

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