

Implementing a Neurotrauma Registry in Latin America and the Caribbean

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Abstract

Background Traumatic brain injury (TBI) has a disproportionately greater impact in low- and middle-income countries (LMICs). One strategy to reduce the burden of disease in LMICs is through the implementation of a trauma registry that standardizes the assessment of each patient's management of care.

Objective This study aims to ascertain the interest of Latin America and the Caribbean (LAC) nations in establishing a shared neurotrauma registry in the regional block, based on an existing framework for collaboration.

Methods A descriptive review was performed regarding the interests of LAC nations in implementing a shared neurotrauma registry in their region. We convened a meeting with seven Caribbean and five Latin American nations.

Results One hundred percent ($n = 12$) of the LAC representatives including neurosurgeons, neurointensivists, ministers of health, and chief medical officers/emergency medical technicians (EMTs) agreed to adopt the registry for tracking the burden of TBI and associated pathologies within the region.

Conclusion The implementation of a neurotrauma registry can benefit the region through a shared database to track disease, improve outcomes, build research, and ultimately influence policy.

Keywords

- ▶ Caribbean region
- ▶ Latin America
- ▶ LMICs
- ▶ neurotrauma
- ▶ traumatic brain injury
- ▶ trauma registry

* These authors contributed equally to this work.

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Introduction

More than 70 million people suffer from traumatic brain injury (TBI) each year.¹ However, TBI has a disproportionately greater impact in specific regions.^{1,2} High per capita rates of TBI at 706 per 100,000 in low- and middle-income countries in Latin America and the Caribbean (LAC) have been described.³

Increased disability where patients must acquire expensive medical treatments and the reduction of economic productivity are some of the reasons why TBI is a public health problem and exacerbated in lower resource communities.^{1,2} Due to the high impact of TBI, some strategies have been proposed to reduce the burden of disease, including prevention strategies and neurotrauma registries as a way of collating data and tracking the current situation of the patient's management.

The neurotrauma registry allows the analysis of almost any patient-related information for the recognition of diseases, the implementation of strategies to reduce the time of surgical care, the monitoring of short- and long-term outcomes for institutional improvement, as well as the development of research tools in the areas where the instrument is applied.⁴⁻⁷ Another added value is related to the provision of financial information that can be valuable for the institutions and governments and its resource management.^{8,9}

A comprehensive understanding of the behavior and the resources available during TBI care is especially important in LAC, as it aids in the development of management protocols that standardize the management of care. It also aids in optimizing the available resources needed to improve TBI care and reduce the burden of disease.

The political and economic movements are strong determinants of health policies in Latin American countries. Large institutions such as the Pan American Health Organization and governments face multiple challenges related to the inequality of their residents.^{10,11} The variety of genetic, cultural, political, and economic structures that have emerged from its conquest to the present are common denominators in the Latin American region. However, health models have been strategically designed to achieve universal coverage for a homogenous population. The implementation of a neurotrauma registry that first standardizes the assessment of the patient's management and second respects the intrinsic characteristics of the population could be particularly useful in the region.¹¹ The diversity of the region and

the population are a strength for the analysis of data related to different sociocultural environments of the same region.¹²

This study aims to ascertain the interest of LAC nations in establishing a shared neurotrauma registry in the regional bloc, based on an existing framework for collaboration.

Methods

We convened a stakeholder meeting with seven Caribbean and five Latin American nations using the personal networks of the authors. We discussed the advantages of establishing and implementing a shared neurotrauma registry within the region. We specifically detailed the requirements of establishing a registry and how the existing Caribbean Community infrastructure would allow for seamless adoption of this registry. These nations we spoke to were Barbados, Curaçao, Jamaica, Trinidad and Tobago, The Bahamas, Guyana, Haiti, Guatemala, Mexico, Argentina, Brazil, and Colombia. We spoke to representatives from each country to gauge their interest and buy-in. The representatives consisted of neurosurgeons, neurologists, neurointensivists, emergency medical technicians (EMTs), chief medical officers, and ministers of health. The breakdown per country of these leaders is as follows: Barbados: a neurosurgeon and chief medical officer; Curaçao: a neurosurgeon; Jamaica: a neurosurgeon and EMT; Trinidad and Tobago: a neurosurgeon and EMT; The Bahamas: a neurosurgeon, minister of health, and chief medical officer; Guyana: a neurosurgeon, chief medical officer, and minister of health; Haiti: a neurosurgeon and chief medical officer; Guatemala: a neurosurgeon; Mexico: a neurosurgeon; Argentina: a neurointensivist; Colombia: a neurosurgeon and chief medical officer; and Brazil: a neurosurgeon and chief medical officer.

All of the meetings took place virtually and lasted approximately 1 hour each. The typical format of the virtual meetings was the following: introduction of all call participants, introduction of the neurotrauma registry, in-depth discussion about the utility of the neurotrauma registry, question and answer session by all participants, verbal agreements by the target audience, and arrangements for the neurotrauma registry managerial team to provide logistical details to the target audience managerial team. Where follow-up was necessary, additional e-mails, calls, or texts were used for correspondence.

A few of the key points we addressed during the in-depth discussion regarding the neurotrauma registry are shown in ► **Table 1**.

Table 1 Key considerations about neurotrauma registry

1. The urgent need for a neurotrauma registry to track traumatic brain injury and associated neurosurgical pathologies within the region
2. Several countries currently utilize neurotrauma registries regularly to improve their research capacity and coordinate clinical care, including Colombia, Ethiopia, and Italy, all of whom have made marked improvements in managing neurotrauma
3. There is no fee for countries who choose to adopt this system, as the costs will be drafted by grants
4. The investment of human capital is minimal given that the technology is relatively simple to use and can be managed by medical students, nursing assistants, or other mid-level providers
5. The bidirectional utility of the registry to impact regional <i>as well as</i> national research capacity

Note: This shows the most important topics discussed around the implementation of a neurotrauma registry in the participating countries.

Table 2 Representatives of countries spoken to during discussions

Country	Neurosurgeon	Neurointensivist	Minister of health	Chief medical officer/EMT
Barbados	Yes	–	–	Yes
Curaçao	Yes	–	–	–
Jamaica	Yes	–	–	Yes
Trinidad	Yes	–	–	Yes
The Bahamas	Yes	–	Yes	Yes
Guyana	Yes	–	Yes	Yes
Haiti	Yes	–	–	Yes
Guatemala	Yes	–	–	–
Mexico	Yes	–	–	–
Argentina	–	Yes	–	–
Colombia	Yes	–	–	Yes
Brazil	Yes	–	–	Yes

Abbreviation: EMT, emergency medical technician.

Results

Of the $n = 12$ LAC nations approached, 100% agreed to adopt a shared neurotrauma registry for tracking the burden of TBI and associated pathologies within the region. We determined agreement as a “yes” from a neurosurgeon, neurointensivist, minister of health, or chief medical officer. ► **Table 2** depicts the LAC nation breakdown. ► **Fig. 1** shows the variables proposed for the shared neurotrauma registry, where patient data are evaluated throughout the evolution of the disease, including demographic data, prehospital, emergency room, surgery, intensive care unit, discharge, and follow-up at 3, 6, and 12 months.

Discussion

This study was a descriptive review examining the interests of LAC nations in implementing a shared neurotrauma

registry in their region. Of the countries approached, 100% agreed in principle and provided verbal agreement to begin the implementation of the neurotrauma registry.

To our knowledge, there is no literature that addresses the need for a neurotrauma registry in LAC nations. More broadly, there is also limited information on the process of convening multiple nations to agree upon neurosurgical solutions for research capacity building and advancements in clinical care.

Based on discussion feedback during our meetings, we believe the LAC nations that agreed in principle to partake in a collective neurotrauma registry did so for a few key reasons. A neurotrauma registry would not be burdensome financially as the cost incurred would be shouldered by our team. Furthermore, the time commitments to run the neurotrauma registry would not prohibit neurosurgeons and their team from primary clinical responsibilities. By humbly

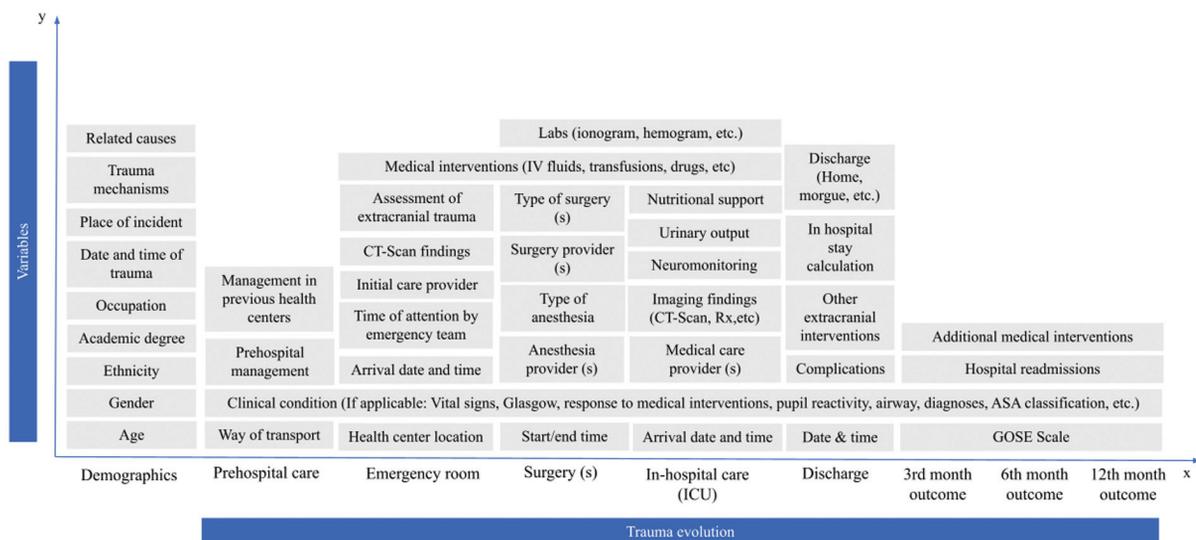


Fig. 1 The neurotrauma registry enables the assessment of the patient’s clinical evolution (x) from the moment of trauma through the subsequent 12 months using a catalog of more than 500 variables (y).

detailing the added value of the implementation of a neurotrauma registry and transparently addressing the concerns of the teams from the LAC nations, we believe that our presentation was successful in securing their partnership and accompaniment in this project.

A unified neurotrauma registry within the region ensures the ability to formulate a comprehensive and readily accessible database, to investigate the nature and extent of neurotrauma, to study the effect of the neurotrauma system, to assess the quality of care, to examine the availability and cost of resources, to evaluate the appropriateness of the system criteria, and to provide ongoing medical accountability.^{10,13}

Moving forward, the aim is to expand and strengthen the partnerships to neurotrauma teams from the remaining LACs to provide coverage to the entire region.

Limitations

Out of convenience and the personal networks of the authors, we initially targeted the countries where prior relationships and contacts had been established. This invariably limited the number of countries approached. Future studies which include more nations can build on our foundational work.

Conclusion

The burden of TBI in the LACs has allowed the development of patient management assessment tools by leveraging the preexisting communication network between nations in this region. A shared neurotrauma registry can facilitate disease tracking, evaluation of outcomes, as well as strengthening local and regional research and policy development for resource utilization.

Conflict of Interest

None declared.

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