

Original Article

## Registry-based pilot epidemiological study of traumatic brain injury in a tertiary trauma care center in Kerala, India – Difficulties encountered during data collection warranting the need for standardized electronic database

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### ABSTRACT

**Background:** Head injury is referred to as a “silent epidemic” globally. Studies regarding epidemiology of head injury are very few especially in Kerala and most have conflicting reports. Unlike developed countries, there is no well-established system for collecting and managing information on traumatic brain injury (TBI) in India, especially in Kerala. The present study shares the difficulties encountered and the insights acquired by conducting a registry-based epidemiological pilot study for collecting a baseline data of traumatic head injury patients in a tertiary care center in Kerala.

**Methods:** The pilot study was conducted to know the efficiency of present reporting system of a tertiary hospital in Kerala. We tried to collect retrospective data from December 2018 to December 2019 in the department of neurosurgery. As there was no standardized protocol or electronic database for data collection in hospital, we made a sample proforma for data collection. The patient details were obtained from medical records (case sheets), resident doctor's, and staff nurse's notes which included demography, clinical details, and radiological findings which were analyzed.

**Results:** We were not able to fill the full details regarding demography, prehospital data, and clinicoetiological details which are important as far as head injury management is considered. The hospital records were grossly inadequate for full retrieval of information. Inadequate case definition and lack of centralized electronic reporting mechanisms were some of the major difficulties we faced obviating the need for collecting, managing, and utilizing epidemiological data using an electronic database.

**Conclusion:** We believe that the present pilot study will give an insight regarding the difficulties encountered in collecting data regarding TBI. This study will be the first of its kind in Kerala highlighting the importance of maintaining a proper head injury electronic registry. The data from this study would definitely guide future experimental operational research on these unexplored areas which will be relevant in head injury policy-making in Kerala as well as in India.

**Keywords:** Head injury, Kerala, Registry

### INTRODUCTION

Head injury is one of the most important public health problems today so much so that it is being referred to as a “silent epidemic” globally. Studies regarding epidemiology of head injury

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are injury are very few, especially in Kerala, and most have conflicting reports.<sup>[1-3]</sup> Unlike developed countries, there is no well-established system for collecting and managing information on traumatic brain injury (TBI) in India, especially in Kerala. Improper case definition, lack of centralized electronic reporting systems, lack of standardized survey protocols, and deficient mortality statistics and proper registry are some of the major obstacles. The present study shares the difficulties we encountered and the insights we acquired following a registry-based epidemiological pilot study for collecting a baseline data of traumatic head injury patients in a tertiary care center in Kerala. The result of this study will definitely guide to develop an electronic database in future for head injury patients which is lacking in Kerala.

## MATERIALS AND METHODS

Descriptive observational pilot study was done based on a 1 year hospital-based retrospective data. Head injury patients attending neurosurgery department and surgery department in ICU/ward/causality) in a tertiary care hospital in Kerala between December 2018 and December 2019 were included in the study as per inclusion criteria. The pilot study was conducted to know the efficiency of present reporting system of a tertiary hospital in Kerala. The tertiary center is a 1500-bedded hospital having 24 hr facilities to manage TBI cases with a team comprising critical care physicians, residents, and faculty from anesthesia and neurosurgery.

### Details of proforma

As there was no standardized protocol or electronic database for data collection in hospital, we made a sample proforma for data collection. The proforma was made in such a way that it was easy to comprehend and easy to fill. All patients having TBI (as per the criteria laid by International Classification of Disease [ICD] injury codes ICD 10) presenting to the department of neurosurgery were included in this study. This included both operated and nonoperated cases.

The patient details were obtained from medical records (case sheets), resident doctor's, and staff nurse's notes which included demographic details, clinical and radiological findings. The proforma used in the pilot study was made and the content validity was checked by the investigator and four other neurosurgeons as per ICD 10 classification. The data were divided into several categories as per ICD 10 norms for neurosurgery. Severity of head injury was assessed by Glasgow Coma Scale and, respectively, classified accordingly as mild, moderate, and severe cases. Demographic data included age, sex, marital status, education, occupation, addiction, and monthly income. Clinicoetiological profile of head injury patients included severity of head injury, neuroimaging findings, and mode of injury. Clinical

outcome included morbidity (seizures, posthead injury headache, and residual neurological deficits), mortality, surgical intervention if any, complications, cost of care, and duration of hospitalization. Outcome was studied based on Glasgow outcome score.

A sample of the tool is included in [Figure 1].

### Statistical analysis

The patient details were entered into Microsoft Excel 2007 and exported to SPSS Version 16 (Chicago Inc.) and analyzed. Statistical method adopted was a thorough descriptive analysis of the percentage of retrievable information on the clinicodemographic variables related to TBI. Inferences were made based on the descriptive analysis data. Statistical test of significance was not employed as the research methodology adopted was a descriptive observation study design. Confidentiality of patient information was maintained. There were no conflicts of interest. This pilot study protocol was approved by the Institutional Ethics Review Committee.

## RESULTS

### Details of fully retrieved information obtained from hospital registry

Out of 112 patients investigated in this study, 97 (87.5%) were male and 15 (12.5%) were female. Most of the patients ( $n = 39$ ) were less than 30 years of age (young adults). Out of 112 patients, 67 patients (60.9%) had mild head injury, 26 patients (23.4%) had moderate head injury, and 19 patients (15.6%) had severe head injury. In 89 patients (79.7%), the cause of head injury was road traffic accident followed by fall in 20 patients (18.8%). Most of the patients ( $n = 60$ ; 53.1%) were managed conservatively. The mean duration of hospital study was 24 days  $\pm$  1.75. Mortality rate in the present study was 10%.

### Information not fully retrievable with the available hospital records

The demographic details such as marital status, education, occupation, monthly income, and addiction which have important bearings on the management of head injury were not adequately filled up due to lack of proper hospital records.

Prehospital details like duration of unconsciousness which has important bearing on prognostication of head injury were not found in medical records.

Clinicoetiological profile of head injury patients neuroimaging findings, laterality of injury, and morbidities such as seizures, posthead injury headache, and residual

| PROFORMA  |   |
|---|---|
| 1. Name :   | 16.Type Of Injury                               |
| 2. Age :  | RTA   |
| 3. Gender : Male <input type="checkbox"/> Female <input type="checkbox"/>                               | Fall  |
| 4. Address :  | Assault   |
| 5. Telephone :  | Others  |
| 6. Education  | 17.Initial CT/MRI Finding                       |
| 7.Marital atatus :Married/unmarried   | Right → Frontal Bilateral                       |
| 8. Religion –Christian / Hindu / Muslim   | Right → Temporal Diffuse                        |
| 9. Place of residence -Rural/urban  | Right → Both                                    |
| 10.Duration of Hospital stay(Including ICU stay) : days   | Brainstem/Cerebellum                            |
| 11.Occupation:professional / businessman / labourer / farmer / gouse wife / unemployed / student        | Left → Frontal                                  |
| 12.What is your monthly household income level? (Include income of all in household who share expenses) | Left → Temporal                                 |
| • <2000   | Left → Both                                     |
| • 2000-5000   | 18.Date Of Injury                               |
| • 5000-10000  | 19.Seizures Y/N                                 |
| • 10000 and above   | 20.Headache Y/N                                 |
| • Declined to state   | 21.Closed Head Injury Y/N                       |
| 13.Mode of Treatment :conservative/surgical   | 22.Operative Records Present/Absent             |
| 14. GCS SCORE : E M V   | 23.Time gap from Injury to Examination Duration |
| Mild 13-15  | 24.Mortality                                    |
| Moderate 9-12   |   |
| Severe < 8  |   |
| 15.Duration Of Impaired Consciousness :Minutes/Hours/Days   |   |

Figure 1: Proforma for pilot study.

neurological deficits were not filled up in a standardized manner as per ICD guidelines. These information are very important when medicolegal aspects are considered.

Percentage of information retrieved with respect to head injury data collected in the pilot study is shown in [Table 1].

### Interpretation based on the results

As mentioned above, inadequate case definition and case ascertainment, lack of centralized electronic reporting mechanisms, and the lack of population-based studies are some of the major obstacles understanding the epidemiology of TBI in Kerala. This information will not only help preventing TBI but also will help policymakers plan health-care programs for managing the disability from head injury. This was found lacking in the records of this tertiary care center in Kerala. As the principal investigator, I urge for a radical change in the way of collecting, managing, and utilizing epidemiological data on TBI.

### DISCUSSION

There were lot of challenges in understanding epidemiology of head injury in Kerala, unlike developed countries; there is no well-established system for collecting and managing information on head injury in India and Kerala. Many

factors hamper the efforts to precisely quantify the burden of acquired brain injury in Kerala. Due to lack of reliable reporting systems, it is difficult to discover reliable statistics even from routinely collected data.<sup>[1-3]</sup>

### Difficulties encountered while collecting data from hospital registry and an overview of present status of hospital records in Kerala

Data taken retrospectively from case sheets and other records in the tertiary hospital showed that there was no standardized protocol for filling data. There were no data collection personnel also. I was not able to fill up most of the information as per the present proforma which is based on ICD-10 classifications. There was also a lack of data sharing and linkage between the existing registries in the state of Kerala to consolidate the available information and to regularly update it at a state, regional level. Unlike developed countries, we do not have linkages between various government departments gathering information about TBI. There was a lack of centralized reporting mechanism, to allow streamlined documentation and utilization of epidemiological data on TBI. Such mechanisms could potentially enhance consolidation of epidemiological information on TBI from various hospital- or population-based registries located in

**Table 1:** Percentage of information retrieved with respect to head injury data collected in the pilot study.

| Variable as in proforma                                     | Percentage of patient data retrievable from present registry in tertiary care center |
|---|--|
| Demographic variables                                       |  |
| Name  | 100%   |
| Age   | 100%   |
| Gender  | 100%   |
| Address   | 100%   |
| Religion  | 100%   |
| Place of residence  | 100%   |
| Date of injury  | 100%   |
| Education/occupation  | 8%   |
| Marital status  | 45%  |
| Occupation  | 7%   |
| Monthly income  | 29%  |
| Clinical variables  |  |
| GCS score   | 100%   |
| Type of injury  | 100%   |
| Mode of treatment   | 100%   |
| Operative records   | 100%   |
| Initial CT/MRI findings                                     | 100%   |
| Duration of hospital stay                                   | 100%   |
| Duration of coma  | 89%  |
| Presence/absence of seizure after admission                 | 87.5%  |
| Presence/absence of headache after admission                | 98%  |
| Prehospital variables                                       |  |
| Time gap from injury to examination duration                | 44.6%  |
| Duration of impaired consciousness before reaching hospital | 5.3%   |

different districts or states. The documentation of disease-related information in most of the hospitals in Kerala is not performed by utilizing a unified method. ICD is the method that should be used for documentation. However, many hospitals in Kerala do not practice documentation based on ICD. Health professionals should be trained to start documenting disease-related information in a standardized format.

Most of the other information intended to collect from the sample proforma were found missing as most of the patient case records were prepared by various grades of doctors (from house surgeons, postgraduates, and faculty members). With the above data, we were not be able to arrive at an epidemiological trend needed for policy-making in head injury. This creates an urgent need for policies and regulation for a centralized information management system in the country that could aid epidemiological investigations on TBI.

### Problems with paper-based records

Lack of electronic documentation and dependence on printed records makes the task of documentation and consolidation of existing data on TBI from various hospitals and registries cumbersome. Paper-based records are also prone to duplication and human errors, which can be significantly reduced by electronic documentation. In addition, paper-based documentation does not allow quick retrieval and analysis of data. Thus, need for trauma registry is the need of hour and it is high time to start.

### Lessons learned from difficulties

The design of a trauma database should correctly identify the defined population based on ICD (10) as the standard to identify the TBI cases. After case definition, we should design a valid and reliable data plan to collect required information. Standardized pro forma will help as an educational tool for better documentation of TBI patients. Too little, data will be of limited value and also too much data will be time consuming and expensive.

### Need for electronic data base

Development of an electronic head injury data registry removes the difficulty encountered with paper-based records.<sup>[1]</sup> It provides easy and quick interpretation of data. Electronic data help in data sharing and linkage between the existing registries in the state of Kerala to consolidate the available information and to regularly update it at a state, regional level. Furthermore, linkages between various government departments gathering information about TBI can be done efficiently. It allows centralized reporting mechanism, to allow streamlined documentation and utilization of epidemiological data on TBI. Such mechanisms could potentially enhance consolidation of epidemiological information on TBI from various hospital- or population-based registries located in different districts or states. A well-designed database can be used to pool multicenter trauma data for epidemiologic reports, to compare effectiveness of care among centers, and to evaluate the performance improvement indicators.<sup>[1]</sup>

### Recommendations

(1) Follow a standard case definition, (2) link multiple hospital-based registries, (3) initiate a state or country wide population-based registry, (4) conduct unbiased population-based studies, and (5) introduce centralized and standard reporting systems for TBI.

### Limitations and future perspectives

The present pilot study was conducted at a single tertiary care center. The study may not reflect the exact situation

in many of the other hospitals. We have done this baseline pilot study in the tertiary care center to ascertain and highlight the difficulties we encountered during data collection and feel that the result of this study was reasonably good to guide future comparative multicenter project studies on these unexplored areas which will be relevant in head injury policy-making in Kerala as well as in India.

## CONCLUSION

We believe that the present pilot study will be an eye opener for filling the existing gap of poor data collection in TBI in developing countries like India. This study will be the first of its kind in Kerala highlighting the importance of maintaining a proper head injury electronic registry. The data from this study would definitely guide future experimental operational research on these unexplored areas which will be relevant in head injury policy making in Kerala as well as in India.

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## Declaration of patient consent

Patient's consent not required as patients identity is not disclosed or compromised.

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Nil.

## Conflicts of interest

There are no conflicts of interest.

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