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Original Article

A minimum data set for traumatic brain injuries in Iran

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ABSTRACT

Purpose: Traumatic brain injury (TBI) is one of the major public health concerns worldwide. Developing a TBI registry could facilitate characterizing TBI, monitoring the quality of care, and quantifying the burden of TBI by collecting comparable and standardized epidemiological and clinical data. However, a national standard tool for data collection of the TBI registry has not been developed in Iran yet. This study aimed to develop a national minimum data set (MDS) for a hospital-based registry of patients suffering from TBI in Iran.

Methods: The MDS was designed in 2 phases, including a literature review and a Delphi study with content validation by an expert panel. After the literature review, a comprehensive list of administrative and clinical items was obtained. Through a two-round e-Delphi approach conducted by invited experts with clinical and research experience in the field of TBI, the final data elements were selected.

Results: A MDS of TBI was assigned to 2 parts: administrative part with 5 categories including 52 data elements, and clinical part with 9 categories including 130 data elements.

Conclusion: For the first time in Iran, we developed a MDS specified for TBI consisting of 182 data elements. The MDS would facilitate implementing a TBI's national level registry and providing essential, comparable and standardized information.

Introduction

Traumatic brain injury (TBI) is one of the major public health concerns worldwide as it results in considerable mortalities and lifelong devastating physical, cognitive and emotional morbidities. This poses significant social and economic burdens on patients, families, and societies. The prevalence of TBI has been increasing since 1990. In 2016 the number of TBI victims was estimated to be 55.5 million individuals around the world.[1–3] Globally, organizations such as the International Initiative for Traumatic Brain Injury Research have launched international collaborative research since 2010 and developed a standardized data collection called Common Data Elements for TBI.[4–7] However, in low- and middle-income countries (LMICs), due to TBI-related limited research funding and efforts, a high-quality data-specific registry at the national level is scarce. Meanwhile, the evidence carried out in high-income countries is not translatable and applicable for LMICs owing to far differences in their care strategies and resources.[3] A TBI-specific registry in which comparable and standardized epidemiological and clinical data are collected is an advantageous mechanism to characterize TBI, quantify its true magnitude and economic and social burdens caused by this injury in LMICs. Besides, it could assist in monitoring and evaluating the quality of care and converting the research results into recommendations for more effective management of clinical conditions. As mentioned before, there is an unmet need for developing a national registry system and minimum data set (MDS) for TBI in LMICs. A MDS tool specifically concerning TBI could provide a set of standardized minimum data for each patient suffering from TBI and unifing definitions for terms and data elements. The data generated from studies implementing the MDS will be comparable and consistent at national and international levels. This would enable researchers and health care professionals to enhance basic and clinical research and practices. This study aimed to develop a national MDS for a hospital-based registry of TBI patients in Iran.

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Table 1
Administrative data elements related to traumatic brain injury inpatients.

Administrative data elements		Agreement level (%)		Final decision	
		First round	Second round	Kept	No. of elements
Demographics					9
	Name[9,10]	100		✓	
	Age[9-11]	100		✓	
	Sex[9-11]	100		✓	
	Marital status[10-12]	69	75	✓	
	Ethnicity[9-11]	53.8	25		
	Race[9-11]	69.2	25		
	Birth country name[10,11]	61.5	100	✓	
	Current country of resident[10,12]	76.9		✓	
	Population size of place of residence[10,12]	100		✓	
	Primary language[10,12]	69.2	100	✓	
	Fluent written/spoken languages[12]	69.2	25		
	Handedness[10-11]	64.2	75	✓	
Socioeconomic status					8
▪	Education				
	Level of education (highest degree)[9-11]	69.2	50		
	Education (number of years completed)[10-12]	69.2	100	✓	
	Parent's years of education; if child[10,12]	69.2	100	✓	
	Classified as a special student[10,12]	53.8	25		
	Ever expelled from school[10,12]	53.8	25		
	Ever failed to advance to the next grade[10,12]	69.2	25		
▪	Employment				
	Current primary occupational status[10,12]	100		✓	
	Job classification category[12]	92.3		✓	
	Employment level[9-11]	38.5			
	Working for paid/unpaid work[10,12]	38.5			
	Number of months with job in last year[10,12]	53.8	25		
	Number of employers[10,12]	33.3			
	Number of people supervised by patient in job[10,12]	38.5			
▪	Cohabits				
	Living situation[9,10]	76.9		✓	
	Primary people living with[9,11]	69.2	50		
	Number of patient's children[12]	69.2	50		
	Number of cohabits[12]	38.5			
	Number of children living with[12]	53.8	25		
	Parents status (dead/alive)[12]	38.5			
	Type of primary caregiver[12]	69.2	25		
▪	Income				
	Annual income of household[12]	53.8	50		
	Number of people supported by the income[12]	38.5			
	Home-ownership[12]	46.2			
▪	Insurance				
	Possession of health insurance[10,12]	92.3		✓	
	Type of health insurance[10,12]	92.3		✓	
▪	Deployment				

	Military status[11,12]	46.2			
	Military occupational status[11,12]	38.5			
	Branch of service in military[11,12]	30.8			
	Military rank[11,12]	30.8			
	Place of deployment[12]	30.8			
▪	Sport				
	Participation in school sports[12]	38.5			
	Type of school sport played primarily[12]	38.5			
	Number of years of school sport played[12]	38.5			
	Type of school sports played secondarily[12]	30.8			
	Participation in recreational sports[12]	23.1			
	Type of recreational sport[12]	38.5			
	Participation in professional sports[12]	84.2		✓	
	Type of professional sport[12]	69.2	25		
	Number of years of professional sports played[12]	46.2			
Past medical history					17
▪	Behavioral history				
	Current alcohol, tobacco or illicit drug usages[9-11]	100		✓	
	Number of days per month with minimum one alcoholic drink[10,12]	69.2	25		
	Average number of alcoholic drinks per day[10,12]	46.2			
	Number of days in last month with 5 for men, 4 for women or more drinks[10,12]	30.8			
	Alcohol usage in more than 1 year ago[10-12]	61.5	25		
	Alcohol usage duration[10,12]	46.2			
	Type(s) of tobacco used[10,12]	61.5	25		
	Type(s) of illicit drug used[10,12]	74.6	50		
	Tobacco or illicit drug usage duration[10,12]	74.6	50		
	Marijuana usage in past[10]	61.5	25		
	Cigarette usage in past[10]	69.2	50		
	Being in trouble in society because of drug use[10]	53.8	50		
▪	History of TBI				
	Number of prior concussions[10, 11]	73.3	50		
	Number of prior TBI[9-11]	92.3		✓	
	Number of prior traumatic injury[10]	73.3	25		
	Number of blasts experienced[10,11]	61.5	100	✓	
	LOC experienced in prior TBI(s)[10,11]	61.5	100	✓	
	Longest duration of LOC in prior TBI(s)[10,11]	61.5	75	✓	
	Youngest age at LOC in prior TBI(s)[10,11]	69.2	75	✓	
	Confusion experienced in prior TBI(s)[10]	76.9		✓	
	Longest duration of confusion in prior TBI[10]	76.9		✓	
▪	Medical history				
	Medical problems/conditions[10-12]	100		✓	
	Medical problems time-points[10,12]	69.2	75	✓	
	Ongoing medical condition/disease[10,12]	84.6		✓	
	History of perinatal neurologic condition[10]	61.5	75	✓	
	History of attention/learning deficit in developmental years[10,11]	84.6		✓	
	History of psychiatric or emotional problems[10,11]	100		✓	
	History of hospitalization for emotional or psychiatric problems[10]	100		✓	
	Prior or concomitant medication (name, dosage, rout)[9-11]	92.3		✓	

	Prior or concomitant medication (frequency, time)[9,10]	69.2	100	✓	
Informed consent and screening					1
	Consent forms for care, treatment, and research[10,11]	100		✓	
	Speech intelligibility test[10,12]	65	25		
	Any problem with speech[10]	73.3	50		
	Galveston orientation and amnesia test[10,12]	66.9	50		
Injury					17
	Injury place[9-11]	100		✓	
	Injury time-point[10,12]	100		✓	
	Reliability of reported injury time[10]	69.2	75	✓	
	If injury time is estimated, the point in time[10]	61.5	75	✓	
	Symptom onset time-point[10]	69.2	50		
	Cause of TBI[10,11]	100		✓	
	Type of TBI[10,11]	100		✓	
	Mechanism of TBI[9-11]	91.7		✓	
	Type of violence[10,11]	75		✓	
	Role in traffic accident[10,11]	91.7		✓	
	Intention[10,12]	75		✓	
	Likelihood of abusive head trauma[10,12]	75		✓	
	Likelihood of influence of alcohol[10,12]	100		✓	
	Likelihood of influence of tobacco or illicit drug[10,12]	100		✓	
	Safety equipment usage/type[10-12]	100		✓	
	Injury body region[10,11]	100		✓	
	Abbreviated injury score[10,11]	91.7		✓	
	Injury severity score[9,11]	100		✓	
Total					52

TBI: traumatic brain injury, LOC: loss of consciousness.

Methods

The MDS was designed in 2 phases, including a literature review and a Delphi study with content validation by an expert panel.

The literature search was performed using keywords in MEDLINE (via PubMed) and Google Scholar in January 2019. In PubMed, the Medical Subject Headings (MeSH) terms “Brain Injuries”, “Data Collection”, “Common Data Elements”, and “Registries” were used. In addition, the Google search engine was used to find the scientific association publications related to the registration of TBI patients. Inclusion criteria were currently ongoing registries and English language. Two researchers extracted all the data elements independently and determined a comprehensive list of administrative and clinical items.

Through a 2-round e-Delphi approach, the final data elements were chosen by 16 invited experts with clinical and research experience in the TBI field. They were informed about the study's process. The experts should only consider the feasibility (or applicability) of elements whose main criteria,[8] including validity, reliability, sensitivity, and specificity were already proven. To this end, they were asked to choose elements with respect to local capacity and limitations of registries, hospital settings, and health care resources in Iran. An online questionnaire was developed which contained dichotomous questions (agree/disagree answers) concerning the necessity of each data element. Each item with more than 75% agreement was included, and one with less than 50% agreement was excluded in the first round. In the second round, the items with 50%–75% agreement were surveyed again, and if there was 75% consensus over a subject, it was included.

Results

Three hundred data elements were compiled in the final list from 3 current large multi-center TBI-registries[9–11] and a national institute of data standardization in the United States.[12] The data elements were classified into 2 parts, including administrative and clinical data (Tables 1 and 2). Fourteen experts participated in the Delphi process, 79% of whom had more than 10 years of experience in trauma center hospitals. In the first round, 152 items were marked as definitive, 58 items were deleted, and 89 items were moved to the next round. In the second round, the experts removed 59 items and accepted 30 items. The resulting MDS had 2 parts, 14 categories, 22 subcategories, and 182 items (Tables 1 and 2, colored cells).

In the first round, items related to the “Injury” and “Post-Discharge Status” categories were approved more than other categories ($n = 17$, 94.4%; $n = 35$, 94.6%, respectively). At the end of the process, “Post-Discharge Status” and “Socioeconomic Status” classifications had the highest and lowest approval rating, respectively ($n = 36$, 97.3%; $n = 8$, 20%).

Table 3 shows 4 included data standards and the number of data elements. The present MDS was the most adapted according to the National Institute of Neurological Disorders and Stroke and the

Table 2
Clinical data elements related to traumatic brain injury inpatients.

Clinical data elements		Agreement level (%)		Final decision	
		First round	Second round	Kept	No. of elements
Pre-hospital presentation					8
	Type of initial medical services provided at scene[10,11]	84.6		✓	
	Initial medical care provider at scene[10,11]	61.5	100	✓	
	Time interval from injury scene to hospital[9,10]	73.3	50		
	Mode of transport from injury scene to hospital[10,11]	84.6		✓	
	Worst vital signs (systolic/diastolic blood pressure, pulse rate, respiratory rate, temperature, arterial oxygen saturation)[9,10,12]	100		✓	
	Hypotensive episode[10-12]	92.3		✓	
	Best GCS[9,10,12]	69.2	25		
	Worst GCS[9,10,12]	100		✓	
	Seizure[10-12]	100		✓	
	Duration of seizure[10,12]	100		✓	
Emergency department					13
	Name of primary or secondary referral hospital[10,11]	92.3		✓	
	Hospital admission time-point[10,11]	100		✓	
	Primary hospital admission time-point[10,11]	73.3	50		
	Reason; if injury late presentation[10-12]	69.2	50		
	Professional referral; if injury late presentation[10-12]	61.5	25		
	Arrival vital signs (systolic/diastolic blood pressure, pulse rate, respiratory rate, temperature, arterial oxygen saturation)[9-11]	100		✓	
	Arrival mode of ventilation (assisted or spontaneous)[10,11]	100		✓	
	Type of respiratory support device[10,11]	91.7		✓	
	Partial pressure of oxygen and carbon dioxide[10,11]	66.7	100	✓	
	Arrival GCS[9,10]	100		✓	
	GCS confounders[9-11]	91.7		✓	
	Arrival pupil reactivity[10,11]	92.3		✓	
	Arrival pupil size[10]	91.7		✓	
	Discharge vital signs (systolic/diastolic blood pressure, pulse rate, respiratory rate, temperature, arterial oxygen saturation)[9,10]	73.3	25		
	Discharge mode of ventilation (assisted or spontaneous)[10]	73.3	25		
	Discharge GCS[10]	73.3	25		
	Discharge pupil reactivity[10]	73.3	50		
	Discharge pupil size[10]	73.3			
	Systemic second insults (hypoxia, hypotension, coagulopathy, aspiration, seizure, cardiopulmonary arrest)[10-12]	83.3		✓	
	Best motor response score[11]	73.3	25		
	Sedated[11]	73.3	50		
	Fluid therapy[9,10]	91.7		✓	
	Emergency department discharge time since injury[10]	61.7	25		
	Discharge destination[10,12]	92.3		✓	

In-patient daily neurologic assessment					5
	Type of GCS (adult/pediatric)[9,10,12]	84.6		✓	
	GCS[9-12]	100		✓	
	Worst GCS during the first 24-hour[10]	61.7	50		
	GCS trend during the first 48-hour[10]	73.3	50		
	GCS confounders[10,12]	83.3		✓	
	Pupils size[11,12]	91.7		✓	
	Pupils shape[12]	50	25		
	Pupils reactivity[11,12]	100		✓	
In-patient physical assessment					12
	LOC[10,11]	100		✓	
	Duration of LOC[10,11]	91.7		✓	
	Source of verification of LOC[10,11]	69.2	25		
	Lucid interval of LOC[10,11]	91.7		✓	
	PTA[10,11]	100		✓	
	Duration of PTA[10,11]	83.3		✓	
	Source of verification of PTA[10,11]	69.2	25		
	AOC[10,11]	91.7		✓	
	Duration of AOC[10,11]	83.3		✓	
	Source of verification of AOC[10,11]	69.2	25		
	TBI symptom/sign category[10-12]	100		✓	
	TBI symptoms/signs[10-12]	100		✓	
	Worsens with cognitive activity[10-12]	83.3		✓	
	Worsens with physical activity[10-12]	83.3		✓	
	Self-assessment of symptoms severity[10-12]	83.3		✓	
	Head circumference in each hospital unit[12]	33.3			
	Weight in each hospital unit[11,12]	25			
	Height in each hospital unit[11,12]	25			
	Weight and height measurement type[11,12]	58.3	25		
Second insults/complication					17
	Complication[9-12]	100		✓	
	Type of complication[10-12]	91.7		✓	
	Wound[10,12]	91.7		✓	
	Type of wound[10,12]	83.3		✓	
	Laboratory abnormalities[10,12]	91.7		✓	
	Hypotensive episode[10-12]	91.7		✓	
	Hypertension[10,12]	83.3		✓	
	Hypoxic episode[10-12]	91.7		✓	
	Inadvertent hypocapnia[10-12]	61.5	75	✓	
	Hyperventilation[12]	71.3	75	✓	
	Cardiac arrest[10-12]	100		✓	
	Seizure(s)[10-12]	100		✓	
	Type of seizure[10-12]	83.3		✓	
	Seizure duration[10, 12]	83.3		✓	
	Hypothermia[10-12]	66.7	100	✓	
	Hyperthermia[12]	83.3		✓	
	Electroencephalography monitoring type[12]	41.7			
	Aspiration of foreign materials[12]	66.7	75	✓	
Therapeutic procedure & inpatient medication					17

▪ Surgery					
	Surgical procedure description[10-12]	100		✓	
	Surgery time-point[10-12]	91.7		✓	
	Duration of surgery[10-12]	91.7		✓	
	Surgery type (elective/emergent)[10,12]	100		✓	
▪ Anesthesia					
	Anesthesiologist visit[10,12]	100		✓	
	Standard American Society of Anesthesiologists monitors[12]	66.7	25		
	Temperature[12]	45.5			
	Partial pressure oxygen brain tissue measurement[12]	53.8	25		
	Inadvertent hypocapnia[12]	69.2	25		
	Hypotensive episode[12]	53.8	25		
	Hypoxia[12]	73.3	25		
	Intra-venous anesthesia drug[12]	66.7	75	✓	
	Arterial line[12]	69.2	25		
	Foley catheter[12]	75		✓	
	Transfusion[12]	100		✓	
	Transfusion type[12]	92.3		✓	
	Extubated at end[12]	76.9		✓	
	Microdialysis glutamate value[12]	33.3			
	Microdialysis lactate to pyruvate ratio[12]	25			
	Cerebral spinal fluid drainage[12]	83.3		✓	
▪ Medications					
	Name of medications[10,11]	100		✓	
	Dose of medication administered[10,11]	100		✓	
	Route of medication administered[10,11]	100		✓	
	Duration of medication administered[10,11]	100		✓	
▪ Hospital units					
	Units hospitalized in[10,12]	69.2	75	✓	
	Timeframe hospitalized in each unit[10,12]	92.3		✓	
Laboratory					11
	Sampling time-points[11,12]	100		✓	
	Type of lab specimen[10,12]	62.3	25		
▪ Chemistry					
	Glucose[10-12]	83.3		✓	
	Glycosylated hemoglobin[12]	8.3			
	Urea[11,12]	50	100	✓	
	Creatinine[10-12]	66.7	75	✓	
	Amylase[11,12]	33.4			
	Serum glutamic oxaloacetic transaminase[11,12]	41.7			
	Serum glutamic pyruvic transaminase[11,12]	33.3			
	Lactate dehydrogenase[10-12]	41.7			
	Alkaline phosphatase[11,12]	16.7			
	Gamma-glutamyl transferase[12]	8.3			
	Total bilirubin[11,12]	33.3			
	Sodium[10,11]	66.7	75	✓	
	Potassium[10,11]	58.3	75	✓	
	Calcium[11]	50	25		
	Chloride[10]	25			
	Magnesium[11]	66.7	75	✓	
	Cholesterol[12]	16.7			

	Triglyceride[12]	16.7			
	Low-density lipoprotein[12]	16.7			
	High-density lipoprotein[12]	16.7			
	Very low density lipoprotein[12]	8.3			
	Apolipoprotein B[12]	8.3			
	Apolipoprotein E[12]	8.3			
	Apolipoprotein A[12]	8.3			
	Atrial natriuretic peptide[12]	16.7			
	Brain natriuretic peptide[12]	16.7			
	Insulin[12]	16.7			
	Cortisol[12]	25			
	Ferritin[12]	8.3			
	Total iron binding capacity[12]	8.3			
	Cobalamin[12]	16.7			
	C-reactive protein[12]	25			
	Creatine kinase-MB[12]	25			
▪ Hematology					
	Complete blood count with differential[10,11]	83.3		✓	
	Prothrombin time/ International normalized ratio[10,11]	75		✓	
	Partial thromboplastin time[10,11]	75		✓	
▪ Other tests					
	Alcohol blood test[10,11]	50	25		
	Toxic drug test[10,11]	66.7	50		
	Pregnancy test[10,11]	33.3			
	Arterial blood gas[10,11]	66.7	100	✓	
Discharge status					11
	Vital status on discharge (alive/died)[10, 11]	84.6		✓	
	Discharge time-point[10, 11]	100		✓	
	Discharge time since injury[10]	66.7	25		
	Destination upon discharge from hospital[10, 11]	91.7		✓	
If Alive;					
	GCS[12]	100		✓	
	GCS confounders[12]	91.7		✓	
	Pupil size[12]	92.3		✓	
	Pupil reactivity[12]	91.7		✓	
	Pupil shape[12]	33.3			
If Died;					
	Death time-point[10,11]	100		✓	
	Place of death[10,12]	84.6		✓	
	Principle cause of death[10,11]	84.6		✓	
	Death cause reliability[10]	84.6		✓	
Post-discharge status					36
	Follow-up time since injury[10]	100		✓	
▪ Socioeconomic					
	Living situation[10]	92.3		✓	
	Reasons for changes in living situation[10]	83.3		✓	
	Education status[12]	84.6		✓	
	Status of school attendance[12]	83.3		✓	
	Returned to work/school after discharge[10,11]	91.7		✓	
	Employment status[12]	91.7		✓	

	Occupational status[12]	75		✓	
	Working hours per week[12]	84.6		✓	
	Reasons for not/fewer working hours[12]	100		✓	
	Employer offer for not/fewer working hours[12]	84.6		✓	
	Current usage of tobacco, alcohol or illicit drug[12]	100		✓	
▪	History of problems				
	Hearing problems[11,12]	83.3		✓	
	Bothering sounds for 5 minutes or more[12]	92.3		✓	
	Dizziness, lightheadedness, feeling of faint, unsteadiness/imbalance[11]	91.7		✓	
	Taste or smell problems[11,12]	91.7		✓	
	Voice, swallowing, speech/ language problems[12]	91.7		✓	
	Movements, mental and level of awareness problems[12]	100		✓	
	Seizure(s)/ epilepsy[12]	100		✓	
	Medication use for seizure(s)/ epilepsy[12]	92.3		✓	
	Experience of new injuries since TBI[12]	83.3		✓	
	Type of the new injury since TBI[12]	76.9		✓	
▪	Treatment				
	Type of out-patient therapy/ rehabilitation[10-12]	100		✓	
	Out-patient therapy or rehabilitation frequency and duration[10-12]	83.3		✓	
	Ongoing out-patient therapy or rehabilitation[10-12]	76.9		✓	
	Type of inpatient therapy[11,12]	100		✓	
	Inpatient therapy duration[11,12]	60.7	75	✓	
	Number of referrals for TBI-related problems[12]	75		✓	
	Type of health care providers referred to[12]	100		✓	
	Name of medication(s) used[11]	100		✓	
▪	Functional status				
	Glasgow outcome scale-extended[9,10,12]	100		✓	
	Disability Rating Scale[10,12]	84.6		✓	
	Performance self-assessment[12]	91.7		✓	
	Needing assistance with daytime activities[12]	100		✓	
▪	Satisfaction				
	Satisfaction with support of close people[12]	75		✓	
	Satisfaction with medical services[12]	83.3		✓	
	Seeking for more effective healthcare service[12]	66.7	25		
Total					130

GCS: Glasgow Coma Scale, LOC: loss of consciousness, PTA: post-traumatic amnesia, AOC: alteration of consciousness

Table 3
Included data standards and number of data elements.

Included data standards	Number of elements			
	All	Extracted for 1st round, $n = 300$	Kept after 2nd round, $n = 182$	Specific for present MDS
Collaborative European neuro-trauma effectiveness research in TBI [9]	56	29	22	0
Transforming research and clinical knowledge in TBI [10]	417	182	132	12
International mission for prognosis and analysis of clinical trials in TBI[11]	198	126	95	2
National institute of neurological disorders and stroke [12]	526	188	134	36

MDS: minimum data set, TBI: traumatic brain injury

Transforming Research and Clinical Knowledge in Traumatic Brain Injury (73.6% and 72.5%, respectively).

The inclusion criteria were considered as patients with TBI who would present at the hospital within 24 h of injury and require an emergency brain CT scan per the Canadian CT Head Rule.[13]

Discussion

For the first time in Iran, we established a TBI-specific MDS comprising 181 data elements. It would facilitate implementing a national-level TBI registry. To date, a handful of studies regarding

TBI have been conducted sporadically in Iran; however, the data were not recorded systematically and did not provide sufficient, comparable, and standardized basic information.[14–17]

Compiling data elements from current large studies collaborating in the International Initiative for Traumatic Brain Injury Research[7] could be one of the strengths of the MDS. Benefit from the good updated resources could result in providing standard and consistent MDS at the international level.[9–12] In addition, applying the Delphi technique would lead to developing the MDS based on the collective knowledge of experts in the field.

Among the reference studies, the approved data elements of our MDS were to a greater extent identical to the National Institute of Neurological Disorders and Stroke[12] as a consistent structure of the Common Data Elements for TBI[11] that could ensure compatibility of MDS.

Data element determination and the level of details should depend on the aim of the study.[11] In designing the current MDS, the administrative and clinical data elements were collected according to the requirements of a hospital-based registry. Consideration of scopes, resources, and capacities could be critical to the success of a registry.[18] Eventually, although we made our best effort to develop a reliable, high-valued MDS concerning TBI, this MDS should undertake pilot studies in Iran in the future to identify its limitations and deficiencies.

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Ethical statement

The study was reviewed and confirmed by the Ethics Committee of Sina Trauma and Surgery Research Center, Tehran University of Medical Sciences, Tehran, Iran.

Declaration of competing interest

The authors declare that they have no conflicts of interest.

Author contributions

Hamid Reza Khayat Kashani designed the original idea. Maryam Edalatfar and Mohsen Sadeghi-Naini carried out the study and collected data. Maryam Edalatfar and Mitra Movahed prepared the manuscript. Mahdi Sharif-Alhiseini supervised the study.

References

1. GBD 2016 Traumatic Brain Injury and Spinal Cord Injury collaborators. Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*. 2019;18:56–87. https://doi.org/10.1016/S1474-4422(18)30415-0.
2. Norton R, Kobusingye O. *Injuries. N Engl J Med*. 2013;368:1723–1730. https://doi.org/10.1056/NEJMra1109343.
3. Rubiano AM, Carney N, Chesnut R, et al. Global neurotrauma research challenges and opportunities. *Nature*. 2015;527:S193–S197. https://doi.org/10.1038/nature16035.
4. Yue JK, Vassar MJ, Lingsma HF, et al. Transforming research and clinical knowledge in traumatic brain injury pilot: multicenter implementation of the common data elements for traumatic brain injury. *J Neurotrauma*. 2013;30:1831–1844. https://doi.org/10.1089/neu.2013.2970.
5. Thompson HJ, Vavilala MS, Rivara FP. Common data elements and federal interagency traumatic brain injury research informatics system for TBI research. *Annu Rev Nurs Res*. 2015;33:1–11. https://doi.org/10.1891/0739-6686.33.1.
6. Maas AI, Menon DK, Steyerberg EW, et al. Collaborative European neurotrauma effectiveness research in traumatic brain injury (CENTER-TBI): a prospective longitudinal observational study. *Neurosurgery*. 2015;76:67–80. https://doi.org/10.1227/NEU.0000000000000575.
7. International initiative for traumatic Bbrain injury research (InTBIR). Available at: https://intbir.nih.gov/.
8. Boulkedid R, Abdoul H, Loustau M, et al. Using and reporting the Delphi method for selecting healthcare quality indicators: a systematic review. *PloS One*. 2011;6, e20476. https://doi.org/10.1371/journal.pone.0020476.
9. Andrew IR Maas. *Collaborative European Neurotrauma Effectiveness Research in Traumatic Brain Injury*. CENTER-TBI; 2013. Available at: https://www.center-tbi.eu/.
10. National Institute of Neurological Disorders and Stroke. Transforming research and clinical knowledge in traumatic brain injury (TRACK-TBI) 2013. Available at: https://tracktbi.ucsf.edu/.
11. IMPACT. International mission for prognosis and analysis of clinical trials in TBI. Available at: http://www.tbi-impact.org/cde/.
12. National Institute of Neurological Disorders and Stroke (NINDS). Common data element 2010. Available at: https://www.commondataelements.ninds.nih.gov/Traumatic%20Brain%20Injury.
13. Stiell IG, Wells GA, Vandemheen K, et al. The Canadian CT Head Rule for patients with minor head injury. *Lancet*. 2001;357:1391–1396. https://doi.org/10.1016/s0140-6736(00)04561-x.
14. Reza A, Riahi E, Daneshi A, et al. The incidence of traumatic brain injury in Tehran, Iran. *Brain Inj*. 2018;32:487–492. https://doi.org/10.1080/02699052.2018.1429658.
15. Kavosi Z, Jafari A, Hatam N, et al. The economic burden of traumatic brain injury due to fatal traffic accidents in shahid rajaei trauma hospital, Shiraz, Iran. *Arch Trauma Res*. 2015;4, e22594. https://doi.org/10.5812/atr.22594.
16. Aghakhani N, Azami M, Jasemi M, et al. Epidemiology of traumatic brain injury in Urmia, Iran. *Iran Red Crescent Med J*. 2013;15:173–174. https://doi.org/10.5812/ircmj.2090.
17. Fakharian E, Mohammadzadeh M, Behdadmehr S, et al. Repetitive traumatic brain injury in patients from Kashan, Iran. *Trauma Mon*. 2016;21, e23869. https://doi.org/10.5812/traumamon.23869.
18. Gliklich RE, Dreyer NA, Leavy MB. *Registries for Evaluating Patient Outcomes: A User's Guide*. third ed. Rockville: Agency for Healthcare Research and Quality (US); 2014.