



Protocol

Design and Implementation of Tabriz Stroke Registry in Northwest Iran

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Abstract

Objective: Stroke is a leading cause of mortality and disability worldwide, and more specifically, it is a challenging issue in developing countries. Stroke registry is a beneficent infrastructure for clinical audits of stroke, as well as related surveillances, epidemiologic studies, evidence-based medicine, and decision-making processes for both clinical practice and health policies. However, few stroke registries have been designed and implemented in Middle East developing countries.

Materials and Methods: Tabriz Stroke Registry (TSR) is a hospital-based prospective multicenter stroke registry, being implemented in 2014 and officially initiated in early 2015 in North-West of Iran. The registry structure was designed by a thorough literature review of the worldwide stroke registries, assessed by an expert panel, and customized to Iranian culture and regional conditions in Tabriz. The software used for the registry used to be offline for a while and is currently online. The registry was confirmed by the Research and Technology Department, Iranian Ministry of Health (MOH) and approved by the local Ethics Committee.

Results: Until now, the relevant data of almost 10 thousand stroke cases have been collected. The collected data include demographics, pre-hospital information, EMS (emergency medical service), clinical findings, primary imaging, lab findings, history of risk factors, drug history, discharge information, follow up, Glasgow Coma Scale (GCS), Modified Rankin Score (mRS), National Institutes of Health Stroke Scale (NIHSS), dysphagia, rehabilitation, complications, trainings and instructions, diagnoses, and treatments (medical, surgical, and interventional) of stroke patients. They are being entered in the registry software and the process of data collection still goes on.

Conclusion: Tabriz Stroke Registry has provided an efficient context for promotion of stroke care clinically and in the related researches, and it can influence the level of these care in North-West of Iran as well as in the national grounds.

Keywords: Stroke Registry, Registry Implementation, Stroke Epidemiology, Stroke Surveillance.

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Introduction

Stroke is the leading cause of mortality and disability worldwide, and all nations, despite their various health systems are exposed to its considerable social, medical and health costs. More than half of the stroke survivors suffer from physical disability, demanding serious assistance for their daily tasks. In terms of developing countries, stroke is a specifically overwhelming challenge,

mainly due to constant increase in the population size and age, as well as in the prevalence of stroke risk factors. Noteworthy, stroke mortalities during the last decades has remained stable or even increased in Asian countries and Eastern Europe while decreasing in most of the western countries [1-3]. Reportedly, in North east of Iran when compared to western countries, age-specific incidence rates of stroke is approximately one decade

lower [4]. The evident heavy burden opposed by stroke, presents the necessity of stroke care promotion, where system failures are more outstanding than the practitioners' failures [5, 6]; therefore, the need for appropriate stroke registries is demonstrated. Stroke registry is a beneficent infrastructure for clinical audits of stroke, as well as related surveillances, epidemiologic studies, evidence-based medicine, and decision-making processes for clinical practice and health policies.

In order to fulfill the mentioned opportunity, Harvard Stroke Registry and the well-known Paul Coverdell Stroke Registry in the USA, as well as the Registry of Canadian Stroke Network were implemented [7-11, 5, 12, 13]. Publications from Stroke Registries in various European countries have emerged including Malmö in Sweden [14], Dijon, Lausanne and Besangon in France [15-17], Frederiksberg in Denmark [18], German Stroke Registers Study Group (ADSR) [19, 20], Tartu of Estonia [21], Arcadia in Greece [22] and Spain [23]. Asian stroke registries were implemented in Russia [24, 25] China [26], Japan [27] Israel [28], Malaysia [29], South Korea [30, 31], Trivandrum of India [32], Ege in Turkey [33], and Khorasan in Iran [34], as well as registries implemented by World Health Organization (WHO) Global Stroke Initiative [35-37]. There are also reports about stroke registries in South American and African countries [38, 39].

The implemented stroke registries in most of the Middle East countries have been performed in a limited time span and except Israeli registry [40], currently, to the best of our knowledge, no running stroke registry in Middle East countries-including Iran is reported.

The city of Tabriz in northwest of Iran, has been the place for outstanding activities about stroke care promotion, representing the urgent necessity for a standard stroke registry. Thereupon implementing Tabriz Stroke Registry (TSR) was aimed.

Materials and Methods

Tabriz Stroke Care Promotion Program and Tabriz Stroke Registry: A history

Tabriz is the greatest city located in Northwest of Iran, acquiring a population of more than two millions. Tabriz University of Medical Sciences is the branch of Iranian MOH and Medical Education, and the first rank university in the region in terms of national rankings. Imam Reza Hospital, the largest medical center in Tabriz, is a tertiary academic medical center, referral for most medical specialties including neurology. The hospital was the first Iranian center to form a stroke team, initiating systematic thrombolytic therapy of ischemic stroke patients, as the first step of their "stroke care promotion program". Many items of this program were launched in Tabriz, including activation of stroke emergency code, pre-hospital notification, and stroke air ambulance which allowed more coordinated stroke care as well as rapid referral of stroke patients all around East Azerbaijan province. After several years of retrospective data collection of stroke patients, from early 2015, Tabriz Stroke registry was implemented as a standard continuous prospective hospital-based registry. Data elements for Tabriz Stroke Registry were

proposed and after numerous sessions of detailed discussions, a minimal data set was approved (Table 1).

Two years after the implementation of TSR, the registry was confirmed by the Research and Technology Department, Iranian MOH and approved by the Local Ethics Committee to expand its activity in the East-Azerbaijan Province.

Considering the continuity of the registry and the good outcomes, recently this registry collaborated with Iranian Stroke Association and Qom University of Medical Sciences in order to form a consortium with support of Research and Technology Deputy of Ministry of Health to extend data collection nationally.

Tabriz Stroke Registry: Overall Design

After extensive literature review about stroke registries worldwide, together with the details of their data elements, the registry of Paul Coverdell in the USA was selected as an appropriate model and it was customized to Iranian culture and regional conditions in Tabriz. This registry includes a great bulk of information about stroke patients as well as a proper executive view to promote stroke diagnosis, treatment, and control [8, 9, 11, 5, 12]. However, proposed designs in the WHO STEP wise approach to stroke surveillance [41] and the manual published for stroke surveillance by EUROCISS Project Research Group [42] were considered as well.

Results

Case Definition and Case Ascertainment

Case definition in Tabriz Stroke Registry tried to integrate already existing definitions and to ensure uniform inclusion of cases. The current WHO definition of stroke is an integrated version which defines stroke as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than twenty four (24) hours (unless interrupted by surgery or leading to death), with no apparent cause other than that of vascular origin". Global clinical signs are accepted only in cases of deep coma or in patients with subarachnoid hemorrhage [43]. Clinical presentations lasting less than 24 hours, diagnosed as Transient Ischemic Attack (TIA), are also included in the registry. Cerebral Venous Thrombosis (CVT) cases are included as well.

Prospective ascertainment of cases are carried out by a combined hot and cold pursuit of patients with potential diagnosis of stroke (or TIA or CVT), after they are admitted to any of the wards in the involved hospitals. The diagnoses are made based on clinical signs and symptoms consistent with stroke presentations in various subtypes, farther confirmed by brain CT scan or MRI [41]. Discharge diagnosis is checked, which has been finalized by expert neurologists, errors in primary diagnoses are corrected, non-stroke cases are omitted, and missed cases are included. Diagnoses are recorded based on ICD 11 classification, as one of the three types including ischemic stroke, hemorrhagic stroke, or other diagnosis. Subtypes are also recorded including thrombotic stroke (and the involved vessel) or embolic stroke (and the source of emboli) as subtypes of ischemic stroke, intracerebral hemorrhage (ICH) or intraventricular hemorrhage (IVH) or subarachnoid hemorrhage

(SAH) as subtypes of hemorrhagic stroke, and TIA or CVT or stroke of uncertain type as subtypes of the other diagnosis. Since TIA signs and symptoms are temporary, TIA cases included in the registry could show the related signs and symptoms, or could have resolved at the admission or at the time of case ascertainment. However these cases are omitted if diagnosed as other than TIA or stroke until discharge.

Data Elements Determined by the Expert Panel

Data elements of Tabriz Stroke Registry were established by an expert panel in the Neurosciences Research Center (NSRC) of Tabriz University of Medical Sciences. The panel included professors of Tabriz University of Medical Sciences who are experts in neurology, neurosurgery, and epidemiology. Data elements reported for the Paul Coverdell Stroke Registry were translated, drafted and proposed to the expert panel. After numerous sessions of discussions on the items and local customs and conditions, a minimal data set was approved by the expert panel (Table 1). All approved items were designed as a questionnaire and printed on both sides of a single A4 sheet. It should be noted that the similar bulk of data usually occupies several pages that makes trouble during data collection and data entry. Therefore abbreviations were used, and it was decided that data abstractors be trained while collecting and entering data.

Data Collection

Data collection started from early 2015 based on the approved data elements. The process is regular, consecutive, in paper-based manner, and is currently going on. These data elements are collected by a combined hot and cold pursuit. The collection process comprises of three phases: admission, discharge and follow up. It includes demographics, pre-hospital info, EMS (emergency medical service) info, clinical findings, primary imaging, lab findings, history of risk factors, drug history, discharge info, follow up, GCS, mRS, NIHSS, dysphagia, rehabilitation, complications, instructions and trainings, diagnoses, and treatments (medical, surgical, interventional) of stroke patients as shown in Table 1.

When a case was admitted to any of the wards in the involved hospitals, with the potential diagnosis of a stroke (or TIA or CVT), the case was identified for the registry data collection. Trained abstractors reviewed the primary data for each case in the hospital record, then they visited the patient and data collection was continued afterwards. The data is further completed on discharge, and by three months follow-up. The registry is prospective and hospital-based, and two academic referral hospitals, named Imam Reza hospital and Razi hospital are involved. Neurology beds in both hospitals constitutes nearly eighty percent of all of approved neurology beds by Iranian MOH for East Azerbaijan Province (the largest province in Northwest of Iran). Data collection was initiated for non-academic hospitals all around the city, which includes the rest of the approved neurology beds of the province; however data from scant non-academic centers were not accessible due to institutional regulations.

During implementation of Tabriz Stroke Registry, when paper-based data collection was fully developed and confirmed,

based upon scientific, executive and accuracy perspectives, the registry software was ordered according to the approved data elements. In the late 2016, the software was designed and provided and digital registration of paper-based data was initiated. The software of the registry used to be offline for a while and is currently online. Until now, paper-based data of almost 10 thousand stroke patients has been collected, together with some cases waiting for their three months follow up, to be completed.

Ethical Issues and Data Security

During admission, patients give their written informed consent for transfer of their data into academic databases including registries. Throughout data collection, no further interventions or tests are defined other than the routine clinical procedures of the hospital and thereupon additional consent taking would be useless. Yet, to keep the cases anonymous, accessibility to their identities and contact information is highly restricted. Members of the stroke team of Tabriz University of Medical Sciences involved in the data collection of the registry, are the health professionals of clinical care for stroke patients, and therefore, they are eligible to have access to the identity and clinical information of their patients. Except the medical care team, other accesses to the data are anonymous with no personal identifications or direct contact information.

Data Ownership and Economic Considerations

Similar to the instructions of the WHO Stroke Surveillance System [42], the Neurosciences Research Center (NSRC) of Tabriz University of Medical Sciences is the data providing center for Tabriz Stroke Registry and therefore is the stakeholder and publisher of the results derived from these data.

Disease specific registries are expensive, and they need to operate for at least one complete calendar year, and preferably for several years to produce meaningful data [42]. The process of these registries require epidemiologists, physicians, nurses and informatics dedicated in a full time manner, which necessitates considerable resources; however as indicated by EUROCISS Project Research Group: “the economic benefits of a good surveillance system clearly exceeds the costs of the registries” [42]. Tabriz Stroke Registry is financially supported by the Tabriz University of Medical Sciences currently through research budgets and partly by Research and Technology Deputy of MOH. This registry has been planned to be continuous and the essential infrastructures are considered and further supports are expected to be gained for more improvements and continuation. Data elements has been designed to provide almost a complete set of information about stroke patients, which could be interpreted into practical solutions for stroke care promotion in Tabriz and other similar regions. Due to reducing economic burdens of stroke, this registry is speculated to be granted by budgets of governmental health systems. These data would also go beyond stroke surveillance and monitoring and turn into the research questions and answers about the role of stroke risk factors or the impact of treatments on survival of stroke patients. This is actually the translation of research “from bench to bedside” and “from bench to community”, therefore appropriate to deserve

some of the practical research budgets, similar to the University of Texas Houston Stroke Registry (UTHSR) which was funded by the Specialized Program Of Translational Research in Acute Stroke (SPOTRIAS).

Discussion

This paper attempted to describe structure and administration of Tabriz Stroke Registry as the first standard continuous prospective hospital-based stroke registry initiated in Iran. This registry is conducted by a combination of cold and hot pursuit of cases for data collection.

Table 1. Core data elements approved for data collection of the Tabriz Stroke Registry.

Items	Records
Patient demographics	Name, surname, national code, gender, birth date and place, medical record code, admitted center, type of insurance, ethnicity, address and telephone number
Pre-hospital information	Place, situation, date and time of symptom onset Date and hour of the last time when the patient was healthy Type of referral to the hospital Date and time of informing EMS* (if any) GCS* obtained by EMS (if any)
Emergency Department (ED)	Date and time of emergency admission Date and time of neurology ward/ICU admission Clinical findings in the emergency ward
Imaging (brain CT-scan)	The Center of imaging Date and time of imaging Presence of hemorrhage
Laboratory tests	Hemoglobin, hematocrit, fasting blood sugar, cholesterol, triglyceride, LDL*, HDL*, albumin
Risk factors	Hypertension, diabetes mellitus, ischemic heart disease, atrial fibrillation, heart valve disease, artificial heart valves, congestive heart failure, myocardial infarction, smoking, etc.
Drug history	Five categories of drugs including: antihypertensive drugs, antiplatelet drugs, anticoagulants, anti-hyperlipidemic drugs, anti-diabetic drugs
Dysphagia state and nutrition type in hospital	Oral nutrition or nasogastric tube or PEG*
Rehabilitation state	
Physical exams	NIHSS* score, mRS* score and GCS* score both in the admission day and in the discharge day
Complications	Aspirative pneumonia, DVT*, Pulmonary Thrombo Emboli, UTI*, etc. Signs and symptoms of stroke Risk factors
Patient training	How to consume drugs Contacting EMS Other trainings
Discharge	Date and time of discharge Type of discharge, in terms of medical order, voluntarily, due to death, etc. Date of death (if dead)
Diagnosis	Primary and final diagnoses (Cases of TIA or CVT were included in the registry) Types [subtypes]: • Ischemic stroke [thrombotic stroke (and the involved vessel) or embolic stroke (and the source of emboli)] • Hemorrhagic stroke [intracerebral hemorrhage (ICH) or intraventricular hemorrhage (IVH) or subarachnoid hemorrhage (SAH)] • Other diagnosis [TIA or CVT or stroke of uncertain type]
Treatment	Surgical or Interventional treatments Thrombolysis by tPA - date, time, place, side effects of thrombolytic therapy Prophylaxis for venous thromboemboli Other medications
Follow up after three months	mRS*, important complications, mortality and the related date (if any)

*EMS: emergency medical service, GCS: Glasgow coma scale, LDL: low-density lipoprotein, HDL: high-density lipoprotein, PEG: percutaneous endoscopic gastrostomy, NIHSS: National Institute of Health Stroke Scale, mRS: modified Rankin Scale, DVT: deep vein thrombosis, UTI: urinary tract infection, TIA: transient ischemic attack, CVT: cerebral venous thrombosis

Traditional disease registries tended to be population-based, and concentrated on epidemiologic variables such as incidence rates. Nevertheless, modern registries including stroke registries in recent decades, mainly aim at improving clinical performance, by monitoring the quality of delivered care. These registries are speculated to practically lead to decreased mortalities, disabilities and complications. This is the reason for hospital-based registries to be increasingly funded [10, 5]. Accordingly, a stroke registry is named “Get with the Guidelines” by the American Heart Association/ American Stroke Association [44-46].

Similar to the Paul Coverdell National Stroke Registry [5], data elements established in Tabriz Stroke Registry by the expert panel were designed to incorporate clinical parameters, which could aid in promoting stroke care, both at the hospital level as well as the community level. Measuring these parameters and incorporating them in clinical guidelines and evidences could clarify challenges and opportunities for further improvements in stroke care. For an instance, barriers to thrombolytic therapy of ischemic stroke and their extent and impact could be extracted accurately from a well-designed stroke registry, and Tabriz Stroke Registry is able to provide this information in this way.

It is, however, notable that unlike population-based registries, hospital-based registries as Tabriz Stroke Registry, could not produce precise epidemiologic variables such as incidence rates and mortality rates, though they could give rough estimates in this regard [42, 41].

There are scant reports implying stroke registries in Middle East including Israel, Ege in Turkey and Khorasan in Iran [34, 33, 40]. The reported registry in Ege was conducted in 1991 - 1995 in prospective manner to form the first systematic epidemiologic database of Turkish stroke patients. As mentioned in the publication in 1998, this Turkish registry was terminated while no other publication was found to point to any other running Turkish stroke registry [33]. Results published from Khorasan indicated similar conduction during 2001 to 2005 [34]. Thereby based on an extensive literature search, except the stroke registry in Israel [40], currently no running stroke registry in Middle East countries, including Iran, is reported. Nevertheless, ongoing stroke registries could keep with the task of evaluating and planning stroke health interventions to reduce its burden unremittingly [5].

Most reported stroke registries, especially in the developing countries, are unfortunately found in the literature by the publications of their epidemiologic reports, not by their standard protocols [25, 47, 34, 15, 18, 33, 38]. Published registry protocols are able to transfer a considerable knowledge regarding design, implementation, maintenance, quality improvement, and application of registries, while an increased need is recognized for implementing stroke registries in various regions. Nevertheless, manual guidelines on stroke registry establishment have been published by WHO and EUROCISS Project Research Group [42, 41], and the numerous reports about the protocols of stroke registries introduce beneficent information [19, 14, 8, 9, 30, 13]. The current report aims at conveying the experience of administering Tabriz Stroke Registry as a fundamental and successful implementation in a developing country of Middle

East, which resulted in the emergence of the Iranian National Stroke Registry.

Specific stroke registries incorporate hot and/or cold pursuit methods for data collection. In hot pursuit, admitted cases to hospitals are identified within few days and information is acquired afterwards, thereby bias would be the least probable, though this approach is expensive. On the other hand, cold pursuit involves collecting data from discharge or expired records in a delayed routine. This pursuit identifies cases in a more optimal manner because final diagnoses are more accurate and the procedure is more economic [42]. Here, a combined hot and cold pursuit is used in Tabriz Stroke Registry, with the aim of introducing the most complete and accurate case identification of stroke.

The broad data elements of Tabriz Stroke Registry brings about the strength of producing comprehensive results in terms of clinical audit and research. Nevertheless, at the same time, this broadness poses the limitation of cost and complexity of data collection and registration. The extent of data elements of a registry could be reversely proportionate with its continuity, unless proper resources are guaranteed.

Implementation of Tabriz Stroke Registry indicates, as previously mentioned about the University of Texas Houston Stroke Registry, that stroke registries are easier to be implemented in hospitals which perform thrombolytic therapy for ischemic stroke, because these centers incorporate relatively strong information recording about patients receiving thrombolysis. Thus, it is suggested that when it comes to implement multi-center stroke registries, prototype testing be initiated from these centers.

Conclusion

Tabriz Stroke Registry has provided the efficient context for clinical audit of stroke care in Northwest of Iran, especially to promote adherence with evidence based standards and facilitate stroke researches. This registry was started to extend in the country and as planned, the development laed to the Iranian National Stroke Registry.

List of abbreviations

EMS: emergency medical service
 TIA: transient ischemic attack
 CVT: cerebral venous thrombosis
 ICH: intracerebral hemorrhage
 IVH: intraventricular hemorrhage
 SAH: subarachnoid hemorrhage
 GCS: Glasgow coma scale
 NIHSS: National Institute of Health Stroke Scale
 mRS: modified Rankin scale
 LDL: low-density lipoprotein
 HDL: high-density lipoprotein
 PEG: percutaneous endoscopic gastrostomy
 DVT: deep vein thrombosis
 UTI: urinary tract infection

Declarations

Ethics approval and consent to participate

The regularities mentioned in the section of “Ethical issues and information protection” are exclusive to Tabriz Stroke Registry. During admission, patients give their written informed consent to transfer their data into academic settings and databases including registries. Implementation of Tabriz Stroke Registry was reviewed and approved by the Ethics Committee of the Tabriz University of Medical Sciences (IR.TBZMED.REC.1396.456).

Consent to publish

Not applicable.

Availability of data and materials

Data sharing is not applicable to this paper as no datasets were generated and analyzed during the current study.

Conflict of interest

The authors declare they have no conflict of interests.

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Authors' contributions

RD has cooperated directly in all parts of this study, MF proposed the idea and subject of the study and supervised design and implementation of the registry, HSB has cooperated for design of this study and guided the general format of the manuscript, MZ has cooperated in the pilot performances of data collection and had a major contribution in preparing the manuscript. All authors have read the manuscript and confirmed its content.

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