

Trauma Registries and Public Health Surveillance of Injuries

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Abstract

Trauma registries are a potential source of part of the data needed for comprehensive public health surveillance of injuries. Like other disease registries, those for trauma are used to collect, store and retrieve data describing the etiologic factors, demographic characteristics, diagnoses, treatments, and clinical outcomes of individuals who meet specified case criteria. In the U.S., the scope of trauma registry case criteria tends to be limited to the most seriously injured individuals who receive hospital care for blunt or penetrating traumatic injuries or burns. Trauma registries are used primarily to monitor and evaluate trauma care at the hospital, regional, and State levels. Multi-hospital trauma registries most often have emerged in geographic areas where emergency medical services (EMS) agencies are planning or administering regional trauma care systems. Several factors have impeded the use of regional trauma registries for calculation of population-based rates of traumatic injury. First, participation in multi-hospital registries often is limited to trauma center hospitals, and even at these specialized centers there are persistent concerns about the completeness of case ascertainment and data quality. Second, injuries that do not require hospitalization usually are excluded from these registries, as are prehospital deaths. Pressures on all acute care hospitals in the U.S. to collect and report standardized trauma care data are mounting, created in large part by hospital accrediting bodies and EMS agencies. These external pressures, coupled with a renewed interest in health care outcomes in general, have created opportunities to extend the coverage of trauma registries, thereby enhancing their potential value for public health surveillance and other purposes.

Introduction

A disease registry is a file of uniform data describing individuals who meet specified case criteria in which medical and demographic data are collected in an ongoing, systematic, and comprehensive way in order to serve predetermined purposes (Brooke, 1974). In the U.S., and in other nations with well-developed vital statistics systems, registration of causes of death provides the basis for the oldest and most successful diseases registries in existence. However, mortality data reveal only the proverbial tip of the iceberg of the public health impact of a disease, and they provide a limited measure of the availability, use, and effectiveness of health care services. Data from registries of nonlethal events, including those for traumatic injury, can provide much of the data needed for more comprehensive population-based surveillance of disease incidence and outcomes.

Emergency medical services (EMS) and trauma care professionals have been at the forefront of efforts to develop trauma registries in the U.S. and elsewhere (Burns, 1991). Much of the impetus for their efforts has come from a need for data with which to monitor and evaluate the quality of trauma care, particularly at trauma center hospitals that participate in trauma care systems. The increasing capacity of computers for storage and retrieval of large amounts of data has been an additional major stimulus to the development of trauma registries. However, these registries are expensive to maintain and they are beyond the means of most developing countries (Chiu, 1993). In this report, the development of computerized trauma registries in the U.S. is summarized, their major uses and limitations are described, and the opportunities further development are outlined.

The Development of Modern Trauma Registries (U.S.)

The first computerized trauma registry in the U.S. was introduced in 1969 at Cook County Hospital in Chicago, Illinois (Table 1) (Boyd, 1971). This registry served as the prototype for Illinois Trauma Registry (ITR), a multi-hospital registry that began operations in 1971. Each of 50 designated trauma center hospitals in the Illinois trauma care system contributed data to the registry, until the loss of federal funds led to the ITR's demise in 1976. A systematic analysis of the ITR experience provides still valuable insights into the operational requirements of

trauma registries (Goldberg, 1980). A secure source of funding, a well-defined patient population, a minimum data set, adequate staffing and training, and a means to estimate the completeness and accuracy of case reporting remain critical operational imperatives.

State and local EMS agencies have had lead roles in developing multi-hospital registries, usually in conjunction with their responsibilities for initiating and maintaining trauma care systems. For example, the San Diego County, California EMS Division initiated a regional trauma care system in 1984, with participation by six designated trauma center hospitals. A multi-hospital trauma registry was established to facilitate a monthly quality of care audit and to measure each trauma center's performance against its contractual obligations with the county EMS agency (Shackford, 1987). Patients included in the registry are those who meet specified case criteria for "major trauma." Because few "major trauma" patients are thought to be transported to non-trauma center hospitals, EMS administrators maintain that the trauma registry database includes virtually all patients who meet the case criteria.

Findings from a recent survey of 50 state EMS directors showed that 24 states had established trauma registries as of 1993 (Shapiro, 1993). The typical state registry was 2 years old, most were established by legislation, and 67% required trauma center participation. Some EMS agencies have succeeded in extending trauma registry coverage to all hospitals in their state, regardless of their trauma center status. For example, Alaska's trauma registry, initiated as a pilot project at seven hospitals in 1988, was extended to all 25 acute care hospitals in Alaska by 1991 (Kilkenny, 1992). However, statewide coverage of all hospitals, and with it the capacity for population-based surveillance of traumatic injuries, remains an exceptional achievement.

Medical professional groups, often with the support of funds from federal agencies, have provided considerable impetus to trauma registry development (Table 1). The Major Trauma Outcome Study (MTOS) was a multi-center study conducted under the auspices of the American College of Surgeons (ACS) from 1982 through 1989 (Champion, 1990). Investigators at more than 140 hospitals used a standardized data collection form to submit data for analysis. Many of the data elements used in the MTOS and the outcome prediction methods developed during the study have been incorporated into trauma registries that remain in operation. At the conclusion of the MTOS, the ACS committed itself to the development of a national trauma registry. This registry began operations in 1993 (Strauch, 1992). The American Pediatric Surgical Association and the American Burn Association also have been active in trauma registry development (Tepas, 1989, Saffle, 1993).

Federal agencies, working with medical organizations and other groups, have helped catalyze and coordinate national-level standardization of trauma registries (Table 1). In 1989, the Centers for Disease Control and Prevention (CDC), the National Highway Traffic Safety Administration, the American College of Emergency Physicians, the ACS and the American Medical Association co-sponsored the first national trauma workshop (CDC, 1989). The deliberations at this workshop led to a set of CDC recommendations for trauma registry case criteria (Table 2) and a set of 95 data elements, including descriptors of the injury event (Table 3). The International Classification of Diseases codes in the case criteria are for injuries that are classifiable as blunt or penetrating trauma or burns. The recommended data elements, in addition to injury event descriptors, describe the patient's identity and demographic characteristics, prehospital care, emergency department care, surgical care, anatomic diagnoses, and outcome. The CDC trauma registry recommendations have been disseminated widely and have been incorporated into public-use and commercial software packages. The U.S. Health Resources and Services Administration (HRSA) is updating and revising CDC's recommendations for trauma registries as part of HRSA's implementation of the federal Trauma Care Systems Planning and Development Act.

Uses and Limitations of Trauma Registries

Trauma registries can serve multiple purposes, including public health surveillance of the causes and consequences of traumatic injury (Table 4). To fully understand the value of trauma registries for public health surveillance and other purposes, it is important to know how individuals and agencies responsible for trauma registry operations prioritize various registry functions. Trauma care professionals and EMS agencies generally place the highest priority on quality of care monitoring and evaluation, which is reflected in the decisions they make about trauma registry case criteria, data content, data collection procedures, data preparation and analysis, and report writing.

The selection of trauma registry case criteria reflects the primary use of registries as tools to help audit the care of patients who have sustained life- or limb-threatening injuries from exposure to excessive blunt or penetrating mechanical force. Patients with these injuries, after transport to the hospital and an initial period of evaluation and treatment in the emergency department, generally are admitted as inpatients. In some instances, these patients are transferred from one hospital to a second hospital for further evaluation or admission. In other instances, resuscitative efforts in the emergency department fail and these patients die prior to hospital admission or transfer to another facility. Regardless of treatment outcome, patients with life- or limb-threatening mechanical force injuries comprise what many clinicians refer to as "major trauma." This category does not include patients whose injuries resulted from other mechanisms, such as poisoning, exposure to extreme cold or other environmental extremes, or submersion in water. Nor does this category include individuals with blunt or penetrating traumatic injuries who are treated and released from emergency departments or those with fatal injuries who die prior to hospital treatment.

The emphasis on "major trauma" patients in trauma registry case criteria has advantages and disadvantages in terms of the value of these registries for public health surveillance of injuries (Tables 5 and 6). On the one hand, the focus on patients with life- or limb-threatening injuries resulting from excessive mechanical force means that clinicians, EMS administrators, health care policymakers, and the public, despite potential differences in how they view the problem of injury, can each comprehend in general terms the causes and severity levels of the injuries that are included in trauma registry databases. This common understanding can facilitate use of trauma registry data for public health surveillance and application of the data to community-wide injury prevention initiatives (Cales, 1989).

On the other hand, the exclusion of prehospital deaths and patients who are treated and released from emergency departments from the category "major trauma" means that the injuries included in trauma registries are not representative of all injuries in the population. This problem is compounded in multi-hospital trauma registries in which participation is limited to trauma center hospitals (Payne, 1989). Further, the category "major trauma" continues to lack a standard definition among clinicians (Valenzuela, 1990). In the absence of such a standard, controversy about case criteria for trauma registries persists (Brotman, 1991), leaving open the possibility that trauma registry databases will differ in the scope of their case coverage over time and across geographic areas.

The emphasis on quality of care also both enhances and limits the value of trauma registries for public health surveillance (Tables 5 and 6). Benefits include the availability of detailed data on injury severity levels and anatomic locations, particularly compared to data available from administrative databases such as hospital discharge files. However, the extensive amount of data collected and stored on individual patients means that trauma registry operations are labor intensive and expensive. Incomplete case finding and incomplete data in some registries continues to limit their value. Expanding the scope of coverage of multi-hospital trauma registries from trauma center hospitals to all acute care hospitals in defined geographic areas can lead to population-based incidence and outcome data. However, shortcomings in case finding and data quality must be resolved for trauma registries to reach their full potential.

Opportunities to Further Develop Trauma Registries

Trauma registries have undergone rapid proliferation in the U.S. in recent years and they now serve a variety of uses and users (Table 7). Still, differences in case criteria and data contents, persistent concerns about completeness and quality, and incomplete geographic and population coverage limit their value for quality of care improvement, public health surveillance, and other purposes. Despite rapid progress, trauma registries are at an early stage of development relative to other disease registries (Pollock, 1989). Experience with these registries, such as those for cancer, may help identify ways to further develop trauma registries. For example, in the U.S., several population-based state cancer registries were created by consolidating local hospital registries.

Several factors favor further progress in developing trauma registries. Hospital accrediting bodies and government agencies responsible for EMS are seeking trauma care data with which to monitor and evaluate trauma care. Professional medical groups active in trauma care are designing or have implemented plans for national trauma registries. Proponents of trauma care systems are advocating more inclusive systems, with participation by all acute care hospitals. These activities, coupled with the interest in health care outcomes generated by the movement for

health care reform, have created opportunities to further development of trauma registries. Capitalizing on these opportunities will require a concerted effort by trauma care professionals, medical groups, public health agencies at the local, state and federal levels, health care services researchers, epidemiologists, specialists in medical informatics and other individuals and groups.

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Table 1. Development of Modern Trauma Registries (U.S.)

Year	Development
1969	Cook County Hospital trauma registry (Illinois)
1971	Illinois State trauma registry
1982	ACS Major Trauma Outcome Study (multicenter)
1985	National Pediatric Trauma Registry
1988	National Trauma Registry Workshop
1990	Trauma Care Systems Planning and Development Act
1993	ACS National Trauma Data Bank

Table 2. CDC-Recommended Trauma Registry Case Criteria

ICD-9-CM condition code 800-959.9

AND one or more of the following:

- Hospital admission
- Interhospital transfer
- Death in hospital

Table 3. CDC-Recommended Trauma Registry Injury Event Descriptors

- Date, time, place of injury
- Work-relatedness of injury
- Protective equipment used
- External cause of injury
- Narrative description of injury
- Blood alcohol and drugs detected

Table 4. Trauma Registry Purposes

- Trauma care quality monitoring and evaluation
- Public health surveillance
- Injury research
- Measuring economic impact of trauma

Table 5. Advantages of Trauma Registries for Surveillance

- Primary focus is life- and limb-threatening injury
- Extensive amount of data on individual patients
- Timeliness of data collection, analysis, dissemination
- Costs are shared, with major contribution by hospitals
- Potential for population-based incidence and outcome data

Table 6. Disadvantages of Trauma Registries for Surveillance

- Lack of standardized definition of major trauma
- Registries are labor intensive and expensive
- Incomplete case finding and incomplete data
- Trauma center registries are not population-based

Hospitalized trauma does not represent all injuries

Table 7. Current Status of Trauma Registries (U.S.)

Rapid proliferation

Differences in case criteria and data contents

Persistent concerns about completeness and quality

Incomplete geographic and population coverage