An evolution of trauma care evaluation: A thesis on trauma registry and outcome prediction models
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Chapter 8
REGIONAL TRAUMA REGISTRY; WORKING ON A COMPLETE AND RELIABLE DATABASE.

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Submitted.
Chapter 8

ABSTRACT

Objective
Process evaluation of the trauma registry within a regional trauma network for the purpose of the legally obliged participation to the Dutch National Trauma Registry.

Design
Drawing up an inventory, descriptive.

Methods
This study evaluated the whole process of trauma registry, from the admission of the patient to discharge or decease, and from the entry of the data to the data transfer to the DNTR. The study consisted of a written questionnaire and an interview. All those involved in trauma registry in a regional trauma network were invited to participate in this investigation.

Results
All people approached (23) from 9 hospitals, filled in the questionnaire and were interviewed. The majority of the hospitals (78%) had registered work agreements to organize trauma registry. A minimum of 12 out of 19 inclusion criteria for trauma registry was known to the majority of the interviewed persons (80%). Two thirds (6) of the hospitals supervised and controlled the inclusion and checked for “missed “patients. Respiratory rate was the vital parameter that was most frequently missing, followed by the Glasgow Coma Scale. The degree of automation of trauma registry and the way it is integrated in the hospital information system strongly differed per hospital.

Conclusion
There is a considerable degree of variation in the implementation of regional trauma registry within a regional trauma network. Principle limitations are found in the absence of control mechanisms for inclusion and missing data, uniform definitions and work agreements, limitative measures for inter- and intra-observer variability in coding injuries, and ICT solutions. As a consequence, there is insufficient compliance with demands for completeness, reliability and consistency of data collection.
INTRODUCTION

Clinical audits play an important role in the continuous process of improvement of health care. Registry and evaluation are used to measure quality of health care and help to identify points for amelioration. The positive effect of clinical auditing was recently described in a systematic review. However, there has also been criticism with regard to the correction of the case-mix in the calculation of the Hospital Standardized Mortality Ratio (HSMR). There are several examples of successful clinical audits. In the Netherlands, the surgical professions play a front role, but also intensive care and perinatal care have their own registry.

Since its foundation in 2009, the Dutch Surgical Colorectal Audit (DSCA; www.dsca.nl) has been developed into a nationwide instrument of quality for surgical treatment of patients with colorectal cancer. The interest politics and insurance companies awarded to DSCA, is illustrated by the fact, that participation in DSCA is included as a Health Inspectorate performance indicator, since the year 2010. Following the DSCA, the Dutch Institute for Clinical Auditing (DICA; www.clinicalaudit.nl) has developed quality registries for breast, oesophageal, stomach and lung cancer. The Dutch Cancer Registry, that registers malignant tumours since 1989, can be regarded as one of the first national registries in the Netherlands. The output of the above-mentioned audits includes (yearly) reports, mirror information, benchmarks and scientific publications.

Data of trauma patients in the Netherlands have been structurally registered since the beginning of this century. In 1998, the Dutch government decided to establish level I trauma centres to improve health care for trauma patients. Alongside the organization of trauma care within a region, trauma centres have the task to establish and maintain a regional trauma registry. The responsibility for data collection is partly delegated to the hospitals that participate in the regional trauma care network.

The Dutch National Trauma Registry (DNTR) was founded in 2006 and the trauma centres supply a mandatory dataset, the so-called MTOS+ dataset, to this national trauma registry. The MTOS+ dataset includes pre-hospital data, vital parameters, coding of injuries, and hospital mortality of all hospitalized, transferred trauma patients, including those who deceased at the Emergency Department (ED) (Figure 1).

A well functioning trauma registry is of great importance to realize quality improvements in the health care for trauma patients. In 2009, the World Health Organization (WHO) published ‘Guidelines for Trauma Quality Improvement Programmes’ and emphasized the importance of adequate trauma registry. Reliability, completeness, and uniformity of data are some of the challenges regional trauma registry centres are exposed to. In order to arrive from data collection to reliable conclusions, it is important to evaluate the process of data collection and data processing. The purpose of this study is to evaluate the process of trauma registry within a regional trauma network.
Chapter 8

METHODS

This study was conducted in the regional trauma network, TraumaNet AMC (TN-AMC), a partnership of 9 hospitals in the region of Amsterdam, the Netherlands, that provides trauma care to an area of 2300 km² with about 1.4 million inhabitants. Since the foundation of TN-AMC in 2008, trauma registry has been introduced step-by-step in the participating hospitals. The number of included patients per year and the main patient characteristics are presented in Table 1.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number</th>
<th>Age in years (mean ± SD)</th>
<th>Gender (% male)</th>
<th>Mechanism of Injury (% blunt)</th>
<th>ISS (mean ± SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>3,889</td>
<td>50,9 ± 28,3</td>
<td>52,1</td>
<td>96,1</td>
<td>7 ± 6</td>
</tr>
<tr>
<td>2009</td>
<td>5,775</td>
<td>52,0 ± 28,8</td>
<td>51,3</td>
<td>96,2</td>
<td>7 ± 6</td>
</tr>
<tr>
<td>2010</td>
<td>6,198</td>
<td>52,7 ± 28,7</td>
<td>50,6</td>
<td>94,5</td>
<td>7 ± 5</td>
</tr>
<tr>
<td>2011</td>
<td>5,689</td>
<td>51,9 ± 29,6</td>
<td>50,4</td>
<td>98,3</td>
<td>7 ± 5</td>
</tr>
</tbody>
</table>

Table 1 | Hospital admissions and patient characteristics regional trauma registry TN-AMC

TN-AMC; trauma network Academic Medical Center, ISS; Injury Severity Score, SD; standard deviation

Figure 1 | Dutch national trauma registry and MTOS+ dataset

MTOS: Major Trauma Outcome Study, ED: Emergency Department, AIS: Abbreviated Injury Scale, ICU: Intensive Care Unit
The whole process of trauma registry, from admission of the patient to discharge or decease, from entry of the data to transmission of the data to the DNTR, has been evaluated using a written questionnaire and an oral interview. The aim was to evaluate the process per hospital. Beforehand, the project leader trauma registry of TN-AMC per hospital compiled a list of people directly involved in trauma registry. These persons were sent a formal invitation to participate in this study, accompanied by background information about the objectives and benefits of the study. Per hospital, at least two persons were invited, dependant on the organization of trauma registry within that hospital.

Prior to the interview, participants were asked to fill in a questionnaire. All items of the mandatory MTOS+ dataset were listed in this questionnaire and people were asked to indicate if these data really were registered, who was responsible for this, and whether these data were manually or digitally recorded.

Participants were involved in a structured interview, questions were formulated by the investigators at forehand. The interview focused at the following aspects in the process of trauma registry:

1. General: What is the benefit of trauma registry? How have responsibilities been divided? How much time is spend on registry? What are the principle problems and improvement issues? Work accords, are they registered?
2. Inclusion: Who performs inclusion? Are people aware of the inclusion criteria and are mechanisms for control in place?
3. Vital parameters: By whom, at what stage in the care trajectory and how are blood pressure, Glasgow Coma Scale (GCS) en respiratory rate registered?
4. Injury coding: Who performs injury coding and what version of the Abbreviated Injury Scale is used? Are these people qualified in injury coding?
5. ICT: Are the data for the trauma registry digitized? Is there a link with the Hospital Information System (HIS)? Is it possible to inter-link the different HIS systems?

The complete questionnaire and the interview can be found on www.traumanetamc.nl.

The interviews were taken by two investigators (PJ, MK), supported by a student medical informatics (VZP). The duration of the interview was 30-45 minutes. The interviews were held in the period from December 2011 to January 2012.

RESULTS

Participants

All people invited from the 9 hospitals of TN-AMC participated in this study. In total 23 persons were interviewed, on average 2.6 persons per hospital. The interviewed persons held the following functions: emergency physicians (3), head nurse ED (8), trauma surgeons (8), ED receptionist (3) and employee surgical secretary (1).
General

The majority of the participants (60%) was informed that trauma registry is mandatory. Seven hospitals had recorded their work agreements for the purpose of the trauma registry. Benefits of trauma registry that were mentioned included: notion of costs, quality improvement of health care, research, education, guidance of policy, notion of trends and extent, quality assurance, mirroring different hospitals. On average 2 hours and 15 minutes per week were spend on trauma registry (13 respondents).

Inclusion of patients in trauma registry

Twelve out of nineteen inclusion- and exclusion criteria were correctly applied by 80 % of the persons interviewed. Less than 80 % of the interviewed persons was familiar with the following inclusion criteria: inhalation trauma patients, victims of hypothermia, patients transferred to hospital department or SEH and patients deceased during transfer to SEH. Less than 80 % of the interviewed persons knew about the following exclusion criteria: patients electively hospitalized for postponed treatment of injuries and patients without injuries who were hospitalized for observation. An ED receptionist did the inclusion in six hospitals (Table 2). Two third of the hospitals (6/9) controlled the correctness of inclusion and also controlled for “missed” trauma patients.

Vital parameters

In all hospitals recorded vital parameters were directly registered after entrance at the ED. All hospitals also registered initial vital parameters of patients ultimately deceased. Two out of nine hospitals did not register vital parameters of all trauma patients, but only “on indication”. One hospital registered respiratory rate in ranges, other vital parameters were registered in absolute values. In eight hospitals an adapted GCS was used for children. All hospitals scored GCS correct for intubated patients as ‘EMV/tube’. All hospitals indicated that respiratory rate was missing most frequently, followed by GCS. This was motivated by the arguments that it not is a part of the routine practice, the importance for lightly injured patients is not recognized and counting of respiratory rate is time-consuming. In all hospitals vital parameters were entered manually into the patient data management system.

Injury coding

All hospitals used the correct version of the Abbreviated Injury Scale (AIS ) (version 1990 update 1998) for the coding of injuries.7 In seven hospitals injuries were coded by data managers of TN-AMC (Table 2). All coders except two had followed a course in injury coding. Information for injury coding was retrieved from discharge letters, radiology reports, laboratory results and operation reports. In eight hospitals injury coding took place within two weeks after discharge or decease, in one hospital directly upon discharge or decease.

ICT

There is a large variation in the extent of automation of trauma registry, the way it is implemented and how it is integrated into HIS. In three hospitals, patients that should be included, are manually ticked at the ED visitors lists. The data of these patients are checked later. Inclusion at the other six hospitals takes place by means of an electronic tick in the HIS. Table 2 presents an overview of the various HIS that are in use and the way data are entered into the DNTR. At the time of this study the Graphical User Interface (GUI), a secured website, was used by some hospitals to directly enter data into the DNTR. Data from the various HIS...
Survey of a regional trauma registry

were extracted, supplemented with other data, such as AIS codes, and subsequently manually entered into the GUI by data managers of TN-AMC. In other hospitals Excel templates were used to compile data, that are being merged into quarterly files. The files are collected by TN-AMC data managers and subsequently sent as bulk files to the DNTR. From all data needed for trauma registry, initially 92 % is digitally entered into the HIS (Figure 2). However, in none of the hospitals there was a direct link between the digitally available data from the HIS and the DNTR.

Support by TN-AMC and feedback

The bi-annual reporting of own data from trauma registry by TN-AMC is appreciated and assessed as sufficient by 8 hospitals. In 7 hospitals there is a need for a recurrent presentation of the use and necessity of trauma registry, notably to inform newly involved employees in trauma care. Besides the bi-annual reporting, there is need for feedback from the DNTR. This concerns comparative information, both within the region as nation-wide.

<table>
<thead>
<tr>
<th>Hospital</th>
<th>City</th>
<th>Level</th>
<th>Inclusion</th>
<th>AIS Injury Coding</th>
<th>Hospital Information System</th>
<th>GUI vs Upload</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Medical Center</td>
<td>Amsterdam</td>
<td>1</td>
<td>ED receptionist</td>
<td>trauma surgeon</td>
<td>AZD, ZIS, Xcare</td>
<td>Upload</td>
</tr>
<tr>
<td>BovenIJ</td>
<td>Amsterdam</td>
<td>3</td>
<td>ED nurse</td>
<td>secretary</td>
<td>ChipSoft</td>
<td>Upload</td>
</tr>
<tr>
<td>Flevo</td>
<td>Almere</td>
<td>3</td>
<td>ED receptionist</td>
<td>data manager</td>
<td>DCC</td>
<td>GUI</td>
</tr>
<tr>
<td>Medical Center Zuiderzee</td>
<td>Lelystad</td>
<td>3</td>
<td>ED receptionist</td>
<td>data manager</td>
<td>XCare</td>
<td>GUI</td>
</tr>
<tr>
<td>Onze Lieve Vrouwe Gasthuis</td>
<td>Amsterdam</td>
<td>2</td>
<td>emergency physician</td>
<td>data manager</td>
<td>ECare / XCare</td>
<td>Upload</td>
</tr>
<tr>
<td>Sint Lucas Andreas</td>
<td>Amsterdam</td>
<td>3</td>
<td>emergency physician</td>
<td>data manager</td>
<td>EPIC</td>
<td>GUI</td>
</tr>
<tr>
<td>Tergooi</td>
<td>Blaricum/ Hilversum</td>
<td>3</td>
<td>ED receptionist</td>
<td>data manager</td>
<td>Mirador</td>
<td>GUI</td>
</tr>
<tr>
<td>Waterland</td>
<td>Purmerend</td>
<td>3</td>
<td>ED receptionist</td>
<td>data manager</td>
<td>SAP</td>
<td>Upload</td>
</tr>
<tr>
<td>Westfriesgasthuis</td>
<td>Hoorn</td>
<td>2</td>
<td>ED receptionist</td>
<td>data manager</td>
<td>ChipSoft</td>
<td>Upload</td>
</tr>
</tbody>
</table>

Table 2 | Regional trauma network TN-AMC

AIS; Abbreviated Injury Scale, GUI; Graphical User Interface, ED; Emergency Department
DISCUSSION

This study shows that there is considerable variation in the way trauma registry is organized within a regional trauma network. With regard to the inclusion criteria, there is sufficient consensus. However, 1/3 of all hospitals has no control mechanisms for missed patients. Complete registry of vital parameters appears to be a problem. Recording of vital parameters for visibly stable patients is being regarded as redundant, due to the fact ED personnel is insufficiently aware of the importance of these values for trauma registry. In most hospitals injury coding is done by data managers of TN-AMC. Due to a lengthy and rather complex systematic of coding, commissioned to a rather limited number of people, presumably the variability of coding will be limited. On average, people spent 2 hours and 15 minutes per week on trauma registry. In this assessment, the activities of the data managers of TN-AMC have not been included (2.3 full time equivalent). The burden of registry is regarded to be the principal disadvantage. This can possibly be diminished by ICT solutions, in particular by linking of HIS with DNTR. Participants are positive about the support given by TN-AMC, notably the bi-annual mirror information is highly regarded.

The legal obligation of trauma centres to participate in DNTR creates an unprecedented opportunity to do research on the epidemiology of traumatic injuries and on the outcome of trauma care for the whole of the Netherlands trauma population. However, this study shows variation in process and procedures in regional trauma registry and therefore presumably as well in comparability of data. There are insufficient control mechanisms to detect missing or wrong inclusions. As a consequence, bias by selection can occur. In an evaluation of the Australian Queensland Trauma Registry, about 5% of the patients appeared to be missed or mistakenly included.10 The number of missed inclusions in regional registry is not known. Missed or mistaken inclusions could be avoided by adequate control, based on basic hospital administration of the responsible specialism or periodic random samples. Respiratory rate and GCS were least reliably registered, according to people interviewed. This agrees with
the annual reports, in which respiratory rate and GCS, were absent for 81% and 56% respectively. In an American study, investigating errors in trauma data registry, failures were found in 55.6% of GCS values recorded upon admission of the patient.\textsuperscript{10} Presumably, vital parameters are more often absent in patients with light injuries, and in instable patients, where the hectic situation may prevent routine recording of control values. For ambulatory ED patients, the number of missing data could be limited, by measuring blood pressure, pulse, and respiratory rate routinely during triage and entering these data into the HIS. A Patient Data Management System (PDMS), can be a remedy for the situation in ED, as it is in the operation rooms and intensive care units. All patient data that are being registered by surveillance- and monitoring apparatus, are being stored and can be read out.

Extended instruction and repeated training are necessary to limit inter- and intra-observer variability in injury coding.\textsuperscript{11} As with the Hospital Standardized Mortality Ratio (HSMR), variation in coding will affect upon the corrected mortality.\textsuperscript{12} Within TN-AMC, injury coding is mostly done by trained data managers, which have easy access to trauma surgeons in the trauma centre. Injury coding has to take place based on complete documentation of the patient, in order to eventually score additional diagnosis. Discharge letters and operation reports only are available after some time and therefore, injury coding should be performed some weeks after discharge or decease. The hospital in our network that coded the injuries on the day of discharge, has adapted this practice, based on this research.

Uniformity of definitions and process is important to guarantee consistency. In a Dutch study about the accuracy of a prospective registry of complications of surgical patients, a number of important complications appeared to be inconsistently registered, whereas 10% of the registered events did not meet the definition of a complication.\textsuperscript{13} Many practical questions and definitions can be recorded best in a manual for trauma registry. The research institute of the American Ministry of Health Care has developed useful directions for registry (http://www.effectivehealthcare.ahrq.gov/repFiles/DEcIDEs_Registries.html#execsum). The American College of Surgeons has established a National Trauma Data Standard to standardize data collection within the national trauma registry (http://www.ntdisdictionary.org/index.html).

Future of national registries
With increasing demands to measure the quality of health care, to compare outcome, and transparency of production and results, the importance of (national) registries will further increase. Policy makers, health care cost insurers, but also the public opinion are demanding disclosure of these data. This study of a regional trauma registry, recommends a number of improvements that may be beneficial also to other registries. It will be of great importance to keep the burden of registry within limits and manageable. By linking of data bases and ICT solutions, the number of ‘double registrations’ can be reduced.

Data managers are indispensable to administer complex and extended files and to guard the quality of data. Direct feedback and transparency of data will increase the involvement of clinicians and helps to maintain their motivation. The design and implementation of (national) registries has to be realised with consultation of the involved professions and needs a wide consensus in order to be successful. Data have to be managed centrally, but data should be available for participants, in order to do research meeting pre-notified standards. The abovementioned measures and conditions will effectively contribute to reliable databases and improvement of the quality of health care, facilitated by the efforts of many people working in the trauma care sector.
REFERENCES


