An interview of trauma registry custodians to determine lessons learnt

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ABSTRACT

Introduction: The international burden of injury is an increasing concern in global healthcare. Developed trauma care systems have reduced death and disability following injury. The ideal platform for surveillance and clinical governance in trauma care quality improvement is the trauma registry. There is a great disparity in the prevalence of active trauma registries between developed and developing countries. More detailed information on lessons learnt would guide those settings, hospitals and regions looking to establish a sustainable trauma registry. The aim of this study was to explore the experiences and perceptions of trauma registry custodians regarding the development of successful and sustainable trauma registries.
Methods: This was a qualitative study using semi-structured interviews of trauma registry custodians. Trauma registries were selected from a wide range of jurisdictions, including single hospital and multi-hospital registries, based in developed and developing countries. Interview transcripts were analysed using thematic analysis; recurrent themes were identified, and a coding frame developed. Quotes were identified to illustrate the themes in the participants' own words.
Results: Twenty-seven interviews, representing 29 registries, were completed. Fourteen of the source registries were based in developed countries (6 single hospital, 8 multi-hospital) and 15 were based in developing countries (9 single hospital, 6 multi-hospital). The analysis generated 15 themes covering resources, data and strategies. The themes dealing with resources were: funding, staffing, information technology and tools for guidance. The themes dealing with data were: data quality, simplicity, injury coding and data utilisation. The themes dealing with strategies were: having a local champion and a clear purpose, stakeholder buy-in, governance, integration, getting started and persistence. For developing countries, the need for a local champion, dealing with data quality through prospective data collection, integration into local resources and keeping it simple were considered particularly important.
Conclusion: The general consensus was that, for a trauma registry to be successful, in addition to adequate funding and trained staff, it needs to be led by a local champion with engagement of key local stakeholders. It should have a clear purpose, pay close attention to data quality and ensure that the data is well used.

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Introduction

The international burden of injury is an increasing concern in global healthcare. It has been estimated that each year approximately five million people die from injury, accounting for 9% of all deaths [1]. Injury causes more deaths than human immunodeficiency virus (HIV), malaria and tuberculosis combined [1]. In some developed countries where systems of trauma care have been introduced, several studies have demonstrated that mortality and disability have declined [2–4]. There have been several global initiatives to improve the quality of trauma care in developing

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countries [5–7]. The ideal resource for surveillance and clinical governance in trauma care quality improvement is the trauma registry.

A trauma registry is a database which, in addition to describing the epidemiology of injury, monitors the processes and outcomes of trauma care, adjusted for injury severity. Trauma registries are critical to improvements in systems of trauma care and have been active in developed countries for decades [6,8,9]. But in developing countries, active trauma registries remain scarce [10].

Although the World Health Organization (WHO) has published guidelines dealing with essential trauma care and quality improvement programs, few resources are available which focus on trauma registry development in low-resource settings [5,6,11]. Similarly, just a small number of studies have examined trauma registry resources and methodology across countries at different stages of development [12]. More detailed information on lessons learnt, from trauma registries based in both developed and developing countries, would guide those settings, hospitals and regions looking to establish a sustainable trauma registry.

The aim of this study was to explore the experiences and perceptions of trauma registry custodians regarding the development of trauma registries and factors that contribute to successful and sustainable trauma registries.

Methods

Design

This was a qualitative study using semi-structured interviews of trauma registry custodians.

Inclusion criteria

Inclusion criteria were defined as follows:

1. The participant held a major role (e.g. director, manager, senior researcher) on behalf of a trauma registry;
2. The trauma registry described was consistent with the broad definition of a dedicated database, prospectively collecting information regarding injured patients at a health facility.

Sampling

Purposive sampling was used to select the custodians of trauma registries to be interviewed; the identification of a suitable and contactable trauma registry custodian was an iterative process. The selection of trauma registries was informed primarily by the bibliography of previous publications and supplemented by the attendance lists of international meetings for which trauma registries were a key agenda item [11,12]. Trauma registries were selected to provide representation from a wide range of trauma registry jurisdictions, including single-hospital and multi-hospital registries, based in developed and developing countries, as defined by the United Nations Human Development Report [13]. Following identification of an eligible trauma registry, contact details for a senior representative were determined by contacting either the corresponding author or that which was provided on the trauma registry website. The introductory email briefly described the purpose of the interview. If the initial correspondents deemed themselves to be unsuitable to speak about the experiences of a particular trauma registry, they forwarded the email on to a more appropriate custodian. On agreeing to participate at an acceptable time, the custodian was emailed the detailed explanatory statement and consent form.

The target sample size was at least 20 trauma registries, with the final number of participants to be determined by the point at which there was data saturation. Potential participants were contacted by email in batches of approximately five at a time to allow for emerging themes to be identified and subsequently explored, interview prompts to be modified as necessary and theme saturation to be detected. This sequential approach to sampling also ensured the broad representation of registry contexts described above and avoided unnecessarily committing participants to interviews that might be subsequently cancelled because of theme saturation. Thirty-nine trauma registry custodians were sent introductory emails, of which 30 replied and 27 participated.

Data collection

A semi-structured interview was designed to capture the experiences, and lessons learnt, of trauma registry custodians. Following consent, the interviewees were provided with the topic guide (Table 1), in English language, in advance. The interviews were conducted by telephone in English and recorded. Most interviews were of 30 to 40 min duration. Almost all interviews involved one participant; for each of two interviews, more than one registry representative participated. All interviews were conducted between 30 September and 20 November, 2014 by one person (GO), an emergency physician and clinical research fellow. A written transcript of the recording was created and shared with the interviewees to confirm its accuracy.

Analysis

The interviews were analysed using qualitative methods, namely thematic analysis [14]. Notes of emerging themes were made during the interviews; this real-time familiarisation informed the monitoring of new themes for subsequent exploration and theme saturation. Following participant review of the interview transcripts, recurrent themes were identified, and a coding frame developed. Where the aspect or direction of a specific theme differed, sub-themes were defined by additional coding. The source data was examined for links between themes or sub-themes and the context of the source trauma registry (single versus multi-hospital registry, developed versus developing country). Initial coding was performed by one author (GO); to ensure consistency, a second author (SB) checked the coding frame against a sample of transcripts. The agreed coding frame was then reapplied to all transcripts by one author (GO). Quotes were

Table 1
Topic guide used for the interviews.

- Please tell me about the major successes or achievements over the history of the registry
- Please tell me about the major failures or pitfalls over the history of the registry.
- What would you like to have achieved with the registry, but didn't?
- Please tell me about the major facilitators or things that have helped over the history of the registry.
- Please tell me about the major challenges or barriers over the history of the registry.
- Please tell me about the major lessons learnt over the history of the registry.
- What would you have done differently, or the same, with the registry if you had your time again?
- What do you believe are the key ingredients to starting a trauma registry?
- What do you believe are the key ingredients for a trauma registry to be sustainable once it has started?
- Please tell me about any resources or tools that you know of that would be helpful for those looking to start a registry from scratch.
- Is there anything else you would like to mention about the success of a trauma registry that has not been covered by the questions so far?