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Long-term patient-reported outcome measures after injury: National Trauma Research Action Plan (NTRAP) scoping review protocol

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ABSTRACT

Background A significant proportion of patients who survive traumatic injury continue to suffer impaired functional status and increased mortality long after discharge. However, despite the need to improve long-term outcomes, trauma registries in the USA do not collect data on outcomes or care processes after discharge. One of the main barriers is the lack of consensus regarding the optimal outcome metrics.

Objectives To describe the methodology of a scoping review evaluating current evidence on the available measures for tracking functional and patient-reported outcomes after injury. The aim of the review was to identify and summarize measures that are being used to track long-term functional recovery and patient-reported outcomes among adults after injury.

Methods A systematic search of PubMed and Embase will be performed using the search terms for the population (adult trauma patients), type of outcomes (long-term physical, mental, cognitive, and quality of life), and measures available to track them. Studies identified will be reviewed and assessed for relevance by at least two reviewers. Data will be extracted and summarized using descriptive statistics and a narrative synthesis of the results. This protocol is being reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines.

Dissemination This scoping review will provide information regarding the currently available metrics for tracking functional and patient-reported outcomes after injury. The review will be presented to a multi-disciplinary stakeholder group that will evaluate these outcome metrics using an online Delphi approach to achieve consensus as part of the development of the National Trauma Research Action Plan (NTRAP). The results of this review will be presented at relevant national surgical conferences and published in peer-reviewed scientific journals.

BACKGROUND

Measurement of long-term outcomes after traumatic injury is of particular concern to the fields of medicine and public health.[1–6] Due to advances in medical technology and trauma care, in-hospital trauma-related mortality has decreased to just 4% in the USA.[7] However, among the 96% of patients who survive to hospital discharge after traumatic injury, many continue to suffer impaired functional status and many die of trauma-related complications long after discharge.[3–5 8 9] Common injuries, such as traumatic brain injury, spinal cord injuries, and lower limb fractures, often result in a high burden of disability and reduced functional status over time.[10] For example, the National Study on Cost and Outcomes of Trauma (NSCOT) and the Functional Outcomes and Recovery after Trauma Emergencies (FORTE) project found that between 40% and 45% of trauma patients had not returned to work 1 year after injury.[2 11] Additionally, these patients are at increased risk of readmission to the hospital[12] and for the development of serious mental health issues such as depression and post-traumatic stress disorder.[2] Despite the need to improve long-term outcomes, trauma registries in the USA only capture in-patient care and do not collect data on postdischarge outcomes or care. This data gap limits research and quality improvement activities that could improve long-term outcomes in trauma patients.

A recent report of the National Academies of Sciences, Engineering, and Medicine calls for the development of a National Trauma Research Action Plan (NTRAP) that spans the continuum of care from the point of injury through rehabilitation.[13] In 2018, the US Army Medical Research and Materiel Command funded a project to develop an NTRAP (under contract number W81XWH-18-C-0179). The three primary aims of that project were (1) to perform a gap analysis of both military and civilian trauma research to identify priorities across the continuum of care; (2) to define optimal metrics to assess long-term functional outcomes in injured patients after hospital discharge; and (3) to identify trauma research regulatory barriers, develop best practices for investigators, and collaborate with deferral entities to define optimal endpoints for clinical trauma research.

To begin systematically collecting long-term trauma outcomes in the USA, it is necessary to determine which instruments, in which patients, and at which time points after injury would be of greatest value. In January 2019, a group of academic, research, surgical, clinical, and public health

experts was convened by the American College of Surgeons Committee on Trauma for a consensus conference on patient-reported outcome measures (PROMs) in Washington, District of Columbia.[14] This consensus conference included keynote presentations and panel discussions on several themes, including (1) which trauma patients are at high risk of adverse outcomes; (2) which instruments should be used to capture relevant metrics on cognitive, physical and mental health, and quality of life; and (3) how best to capture these data to support this initiative on a large scale. The discussions at this meeting helped inform the design and inclusion criteria for the protocol described in this article, which aimed to undertake a scoping review of the evidence on the measures that are available for tracking functional and patient-reported outcomes after injury. The results of the scoping review described in this article will be used to inform a Delphi survey of stakeholders for aim 2 of NTRAP.

PATIENTS AND METHODS

This protocol is being been reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines.

Included study design

We will include randomized control trials, which are considered the top level of evidence for decision-making. However, according to initial preliminary searches, we have identified a limited number of these study types in our population group of interest. For that reason, we will expand our search to include cohort studies, case–control studies, and cross-sectional studies.

Searches

The following sources will be searched for primary studies:

- PubMed.
- Embase.
- Checking of citation lists of included studies and relevant reviews.

A combination of text words and Medical Subject Headings (MeSH) terms (for PubMed) relating to long-term PROMs after injury, identified in the preliminary searches of the FORTE project,[15] will be used. Terms that will be included in the search are described in detail in online supplementary appendix 1B. Publications will be restricted to those published after January 10, 2013, when the National Quality Forum published a landmark report on patient-reported outcomes in performance measurement. We will also restrict publications to those published in the English language.

The search results will be downloaded and imported into EndNote (Thomson Reuters, NY). EndNote will be used to identify articles for inclusion using the predetermined eligibility criteria (see the "Inclusion/exclusion criteria" section for details). Duplicate records will be identified and removed using the EndNote duplicate tool. Then, study selection based on the inclusion/exclusion criteria will be performed manually in two stages using the Covidence online software:

1. Title and abstract screening will be performed by one researcher and checked by another researcher for consistency.
2. Full-text reading will be performed by two researchers and checked for consistency.

Where a difference between researchers occurs, agreement will be performed by consensus or by including a third researcher. A PRISMA-ScR study flowchart will be used to demonstrate the inclusion/exclusion process.

Inclusion/exclusion criteria

Inclusion criteria

- Studies that follow up patients between 6 months and 10 years after injury.
- All types of acute physical traumatic injuries and severity (including burns).
- Studies involving study subjects ≥18 years old (at the time of the traumatic episode).
- The studies analyzed primary data.
- The studies are systematic reviews, randomized control trials, cohort studies, case–control studies, and/or cross-sectional studies.

Exclusion criteria

- The studies do not measure long-term patient-reported outcomes.
- The studies examine chronic injuries occurring during a long time period (eg, stress fracture) and/or iatrogenic injuries.
- The study population is mixed with non-trauma patients.
- The studies do not report time of follow-up after the injury.
- The studies' outcomes are only patient satisfaction or health-care service.
- The publications are narrative reviews, case series of less than 20 patients, case reports, conference presentations, or study protocols.

Data extraction

All data specific to the review question and necessary for the narrative synthesis of outcomes will be extracted. These include information on the study characteristics, population baseline characteristics, instruments used, and outcome measures. The list of variables that will be extracted from selected articles is presented in online supplementary appendix 1C. As an additional step, corresponding authors will be contacted when extracted data are considered missing or ambiguous from the screened studies.

Critical appraisal of studies and data extraction will be conducted by pairs of reviewers. One reviewer will independently extract the data from the included studies, and a second reviewer will confirm these findings. Disagreements will be resolved by a third reviewer.

Data summary and synthesis of results

The general characteristics of each study will be summarized, and a narrative synthesis of the results of the selected studies will be presented following the PRISMA-ScR guidelines. The collected findings will provide an overview of the quantity of research rather than an assessment of the quality of individual studies. Subgroup analyses by the following four domains will be conducted: mental health, physical health, cognitive functioning, and social functioning. Within each category, we will identify the outcome measures/instruments used and identify potential gaps within the literature.

DISSEMINATION AND DISCUSSION

This scoping review will provide information regarding the currently available measures for tracking functional and patient-reported outcomes after injury. This review will summarize metrics that are already being collected for research and some trauma registries.[16 17] This will then inform the Delphi-based consensus process to provide recommendations on a proposed list of PROMs to be included in trauma registries. Feasibility of collecting these PROMs will be an important factor considered by the panels. By including patients and caregivers in Delphi consensus survey panels, we will also ensure these PROMs

are relevant and important to the trauma patients. The results of this review will be presented at relevant national surgical conferences and published in peer-reviewed scientific journals.

We aimed to capture the range of metrics that are being used to track long-term outcomes for adults after any injury type, including thermal injury. Potential limitations of this study include the heterogeneity of measures and outcomes evaluated and the potentially reduced number of studies in subgroup analyses by patient population or type of outcome. This is an important next step in the development of the NTRAP, which will inform further research and investigation to advance the field of injury care. Because injury remains the leading cause of death and disability in the first 44 years of life, this project will help inform the future of trauma care to optimize recovery and reintegration into society of all those who suffer from these sudden and life-altering events.

Correction notice The credentials for Maxwell Braverman in the collaborators group has been corrected from MD to DO.

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Contributors All authors contributed to the study design and article writing/provided critical review.

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Competing interests None declared.

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