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An Introduction to Patient Reported Outcome Measures (PROMs) in Trauma

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Abstract

Increased survival rates from traumatic injury have resulted in more people living with disability and reduced quality of life. To understand how peoples' quality of life is affected following a traumatic injury and the effects of that injury on their health and wellbeing, it is important to capture patients' perspectives of their own health. Patient Reported Outcome Measures (PROMs) are questionnaires, completed by patients, which can be used to measure the symptom burden associated with trauma and its treatment, and impact on quality of life. PROMs have a wide variety of uses which are relevant to trauma. In a research setting, PROMs can be used to assess the effectiveness of treatment and burden of disease. In a clinical setting, PROMs have the potential to inform and guide patient-centred care and clinical decision making. Collected as part of trauma registries, PROMs can be used at an aggregate level to inform improvements and uphold the quality of trauma care. This literature review explores and summarise the key current and potential future uses of PROMs in trauma research, routine clinical practice and registries.

Key words

Trauma; Patient Reported Outcome Measures; Quality of Life; Trauma Registries

Introduction

Traumatic injury is a leading cause of death; however, improvements in trauma care have led to reductions in injury-related mortality.(1) Consequently, increased survival rates have resulted in more people living with disability and reduced quality of life.(2) This rising number of major trauma survivors has created the need for a change in the approach to clinical practice and rehabilitation for this population.(2)

Clinical outcomes, such as mortality rates, are widely recognised as indicators of health; however, they do not adequately capture patients' health-related quality of life.(3, 4) Evidence suggests relying on clinical outcomes alone may underestimate the impact of a condition.(5) To understand how peoples' quality of life is affected following a traumatic injury and the effects of that injury on their health and wellbeing, it is important to capture patients' perspectives of their own health. One way to address this is through the use of Patient Reported Outcome Measures (PROMs).

What are PROMs?

PROMs are questionnaires, completed by patients, which measure patients' own experience of their health such as symptoms, mobility, mental health and social function.(6) As opposed to clinical outcomes which are reported by health care providers, PROMs provide health status reports or outcomes obtained directly from patients, without interpretation of patients' responses by a clinician or anyone else.(6) PROMs measure constructs, such as health-related quality of life (a combination of physical, mental and social aspects) or specific dimensions of health; for example, mood.(7) Broadly, PROMs are categorised as either generic or condition-specific. Generic PROMs are designed to be used in any patient population and, therefore, enable comparison across different health problems or populations.(8) Generic PROMs are useful when there are no condition-specific PROMs available or when patients have multi-morbidities.(8) For example the Short Form-36 (SF-36) is a health-related quality of life questionnaire which includes 36 questions covering eight domains (physical functioning, role limitations-physical, bodily pain, general health, vitality, social functioning, role limitations-emotional and mental health) (Table 1).(9) However, generic PROMs may not provide an adequate level of detail and they can be less sensitive to capturing change.(8) On the other hand,

condition-specific PROMs are developed for a particular disease, condition or injury; these PROMs specifically measure problems or aspects of health relevant to that condition and can be more responsive to change.(8) For example, the Hospital Anxiety and Depression Scale (HADS) which comprises 14 questions relating to anxiety and depression (Table 1).(10) Often a combination of generic and condition-specific PROMs are used.

PROMs have a wide variety of uses relevant to trauma. In a research setting, PROMs can be used to measure the effectiveness of treatment and are also increasingly used to monitor adverse events.(11) Some PROMs, such as the EuroQol 5-Dimensions questionnaire (EQ-5D) (Table 1), can be used to calculate quality adjusted life years (QALYs) and are frequently used in economic evaluations.(12) A QALY is a measure of the value of health outcomes which takes into account both quantity (years of life remaining) and quality of life lived; one QALY is equal to one year of life in perfect health and death is considered to be equivalent to 0. EQ-5D can be used as the quality of life score used in the QALY calculation.(12) In a clinical setting, routine PROM collection has the potential to inform and guide patient-centred care and clinical decisions; increase patients' satisfaction with their care; and decrease healthcare visits.(3, 13, 14) There are a number of national and regional trauma registries, to which PROMs could provide information from the patients' perspective to improve the efficiency and quality of trauma care.(15)

This review will explore and summarise the key current and future uses of PROMs in trauma research, routine clinical practice, and registries. The review was informed by literature identified from a search of Medline, from inception to April 2018. The search strategy included the following terms: trauma (wounds and injuries), PROMs (patient-reported outcomes, outcomes assessment, quality of life, surveys and questionnaires), systematic reviews and registries. The review included studies of trauma injury, which were published in English. Traumatic injury was defined as physical trauma/ injury and does not cover psychological trauma. Non-trauma literature and resources relating to PROMs were also used to inform this review.

PROMs in trauma research

PROMs have a variety of uses in trauma research, including to: measure the effectiveness of an intervention; establish the impact of trauma on quality of life/ symptoms; evaluate cost effectiveness; and audit trauma services. Examples of trauma studies which have utilised PROMs for each of these purposes are presented in Table 2.

PROMs are commonly collected in trauma research.(16-21) Systematic reviews of PROMs used in studies of burns,(17) upper extremity trauma,(19) facial trauma,(20) hand and wrist trauma,(16) traumatic brain injury,(21) and major trauma(18) demonstrate the large variety PROMs which are being used. However, only a small number of these PROMs are injury-specific (Table 3). Furthermore, there is variation in the number of different PROMs used for research across types of trauma; for example, 77 different PROMs were identified from burns studies(17) compared to nine identified from hand and wrist trauma studies.(16) Despite the large number of PROMs used in trauma research, clinical outcomes are still more common; Jayakumar et al (2017) found that, in upper extremity trauma studies, the majority of the 114 outcomes identified were clinical based outcomes (53%; 76/144).(19) Furthermore, there is great diversity in which PROMs are used in different studies; a systematic review of PROMs used in major trauma found that 21 of the 38 PROMs identified were only used once,(18) which has implications for drawing comparisons across studies and meta-analyses. This highlights the need for increased standardisation of measures, through the development and use of core outcome sets which include both clinical and patient-reported outcomes.(22, 23)

A key consideration for selecting which PROM(s) to use in trauma research is the PROM's psychometric properties, which ideally should be established in the trauma population of interest and encompasses validity, reliability and responsiveness.(24) Validity refers to the extent to which a PROM measures what is intended, reliability is whether PROM results are reproducible, and responsiveness is ability of the PROM to detect change.(24) Griffiths et al (2017) found that only 17 (four condition-specific and 13 generic) out of 77 PROMs used in burns studies were psychometrically validated with adult burns patients.(17) Similarly, in a systematic review of hand

and wrist trauma, only two (out of nine) PROMs had evidence of reliability, validity, and responsiveness in patients with traumatic injuries to the hand and wrist.(16) Validity, reliability and responsiveness are context dependent; therefore, using a PROM which has not been validated in the trauma population of interest can have implications for the findings and interpretation of results. Resources are available to aid researchers' selection of PROMs, such as the PROQOLID™ which is a database of PROMs that includes information about psychometric properties.(25)

Rationale for assessment should inform choice of PROM for trauma research. Generic measures, such as SF-36, are commonly used in trauma studies(17, 18, 21) and are valuable for comparisons across studies and different conditions. On the other hand, condition-specific PROMs provide more detailed assessment of symptoms relevant to trauma; for example, the Burn-Specific Health Scale (BSHS) which includes items specially relevant to burn injury such as heat sensitivity and body image.(26) Therefore, use of both generic and condition specific PROMs may be valuable for trauma studies. It is essential for researchers to collaborate with trauma survivors to ensure that content of the PROMs capture domains which are relevant to them and that PROMs are acceptable to complete.

Given the diversity in types of traumatic injury and the impact of injury on symptoms and quality of life, it may be challenging to identify PROMs that, in combination, may capture all areas of interest without causing excessive burden of completion to participants. An alternative option is use of a computerised adaptive test (CAT) such as the Patient-Reported Outcome Measurement Information System (PROMIS). PROMIS is part of the national person-centred assessment resource which includes a range of PROMs suitable for adults and children with long-term conditions. It has a selection of PROMs capturing a range of physical, mental and social health patient-reported measures. Also available is the NEURO-QOL assessment database for use with adults and children with neurological conditions such as those resulting from traumatic brain injury.(27)

Accurate design, implementation, analysis and reporting of PROMs in trauma is essential to minimise research waste; however, this is often suboptimal.(28) To ensure trauma studies capture PROMs in a scientifically rigorous way, PROM data collection should be comprehensively detailed in the protocol. Protocol development should follow the SPIRIT PRO Extension guidelines (Standard

Protocol Items: Recommendations for Interventional Trials Patient Reported Outcomes), which provide recommendations for items that should be addressed and included in clinical trial protocols in which PROM are a primary or key secondary outcome.(29)

PROMs in trauma clinical practice

PROMs have a valuable role in routine clinical practice at an individual level to promote patient-centred care and at a macro level to collect data for audit and quality assurance.(30) Capturing the patients' perspective through PROMs can improve communication between patients and healthcare providers,(31) facilitate treatment decisions, and monitor recovery and rehabilitation.(32) Quantifying patients perceptions is important given that patients and clinicians have different priorities and evidence demonstrates there is a discrepancy between patient-reported and clinician-reported symptom burden, with clinician often underestimating symptom burden.(33) Collection of PROMs in routine clinical practice has been shown to increase patient satisfaction.(34) Furthermore, routinely collected PROMs in clinical care will generate longitudinal databases of patient-reported outcomes which could be utilised for epidemiological research.

Integration of the patient voice through the use of PROMs in clinical care is particularly important in the context of trauma where there is high heterogeneity between patients in terms of their experience of the traumatic injury, symptoms and severity.(30) Furthermore, sequela of traumatic injury is often subjective, such as pain and psychological impact. In the United Kingdom (UK), PROMs are routinely collected pre- and post-operation for elective hip and knee replacements;(35) however, PROMs use in non-elective traumatic injury clinical care is variable.(31)

There are a number of barriers to implementing PROMs in routine clinical care, including: practical considerations (workload required to collect and analyse PROMs); skills/ training needs (knowledge about use and interpretation of PROMs); and healthcare professionals' attitudes (views about PROMs and reluctance to change practice).(36) To facilitate meaningful use of PROMs in routine clinical practice, an infrastructure needs to be in place to integrate PROMs into normal routines so that PROM

data collection is not disruptive or burdensome.(32) Technology has an important role to play in improving the efficiency of PROM collection and feedback.(37) Healthcare providers should receive training and clear guidelines to understand: rationale for PROM collection; measurement properties of PROMs (such as validity, reliability, measurement error and responsiveness); how to administer and interpret PROMs; and how to use results to inform clinical care.(36) To optimise PROM use, healthcare providers should be included in the planning/ implementation stage and transparency around the rationale for data collection is essential.(36)

PROMs in trauma registries

Trauma registries are databases which document information about traumatic injury patients and their acute hospital care, some registries also collect follow-up data post-discharge.(15) Data from these registries is valuable for many different purposes, including quality improvement, epidemiology, policy development and research.(38) There are a variety of different regional and national trauma registries which have different inclusion criteria and collect different types of information. Most registries include information on demographics, mechanism of injury, clinical diagnosis (ICD-9), length of stay and hospital mortality.(38) Outcomes in trauma registries are usually limited to survival and clinical outcomes; very few registries collect post-discharge data and even fewer collect PROMs.(39) Routine collection of PROMs in trauma registries could provide a better understanding of the long-term burden of trauma and inform clinical decisions and policy, demonstrating the use of PROM data at an aggregate level.(15) It might also facilitate monitoring of long-term outcomes based on innovative practices being introduced during the golden hour and during the initial acute care phase of trauma management.(40)

An example of successful routine collection of PROM data from a trauma registry is the Victorian State Trauma Registry (VSTR), established in 2001, which collects information about major trauma patients from every hospital and healthcare facility in the state of Victoria, Australia.(41) Information is collected on patients' function, health status, pain and return to work using the following measures:

Glasgow Outcome Scale-Extended (GOS-E), SF-12, EQ-5D, a five-point Likert scale for disability, a numerical rating scale for pain and questions on return to work. Data is collected at six, 12 and 24 months post-injury by telephone interview (Table 4).(42) The GOS-E, disability scale and return to work questions can also be completed by proxy. Although telephone interviews are a resource intensive approach, they results in high response rates (>80%).(42)

In Europe, the largest trauma database is the UK's Trauma Audit and Research Network (TARN), a registry of hospitalised major trauma patients in England and Wales.(43) The registry was established in 1988 and its main aim is to drive improvements in trauma care through audit and performance comparisons.(43) TARN are piloting collection of PROMs (began in autumn 2014) at baseline (as soon as possible post-injury) and six months by postal questionnaires. The PROMs collected are: EQ5D-5L, a Patient Reported Experience Measure (PREM) and questions on return to work/ education; GOS-E is additionally collected at six months.(43)

In the United States of America (USA), PROM data collection has been piloted as part of the Functional Outcomes and Recovery after Trauma Emergencies (FORTE) project at three trauma centres in Boston.(44) The following PROMs were collected at six and 12 months via telephone interview: the Trauma Quality of Life Instrument, SF-12, a post-traumatic stress disorder screening questionnaire, and questions on return to work.(44) Longitudinal PROM collection was found to be feasible and identified that a significant proportion of patients had physical and emotional impairment at six and 12 months.(44)

In Australia and New Zealand, PROM collection was piloted in the Burns Registry of Australia and New Zealand (BRANZ). Five centres piloted collection of the following PROMs at one, six, 12 and 24 months: the BSHS-Brief; SF-36; Sickness Health Profile (SHP); Brief Fatigue Inventory (BFI); and an Itch questionnaire.(45) The PROMs were administered at using different methods (telephone/ face-to-face interview or post); however, follow-up rates were low: 63% at one month, 47% at six months, 40% at 12 months and 21% at 24 months.(45)

Trauma registries are resource intensive and require a large amount of time and money to collect and quality check data.(15) However, their value has been demonstrated through the impact of improvements in trauma care on reduced mortality rates.(46) Mortality has traditionally been used to assess trauma outcome and quality of care at a system level; but, given improvements in survival,(1) it is increasingly important to capture data on function, cognition, psychological impact and quality of life.(47) However, PROM collection can add to the resource burden, including costs required for administration of PROMs (e.g. telephone calls/ post), PROM licence fee (if applicable) and staff salaries and facilities (such as office space). In 2010, the VSTR estimated the additional collection of PROMs data was 90,000 AUD annually (six, 12, 24 months for 2,000 patients).(42) Post-discharge PROM collection can be particularly challenging; postal questionnaires have been found to have low response rates;(48) however, interviews are time consuming and may require training or specialist staff.(42)

To increase sustainability of PROM collection, registries need to improve efficiency of data collection. An optimal model would comprise routine electronic PROM capture integrated into clinical practice which directly feeds into the trauma registry when required. However, post-discharge PROM collection requires multiple different data collection methods, including proxy, to address patients' preferences and abilities.

Similar to PROMs use in trauma research and clinical practice, selection of PROMs is a key challenge for trauma registries. Registries collect aggregate data; therefore, diversity of types of traumatic injury and the impact of the injury on symptom burden and quality of life has implications for outcomes selected (e.g. function, mood, cognition), measurement properties and mode of administration.(49) Multiple condition-specific and generic PROMs may be required; however, resource restraints and patient burden must also be considered. Rationale for PROM collection is an important consideration and different stakeholders may value different outcomes, for example, policy makers may prioritise return to work whereas patients may prioritise pain and quality of life.(49) Trauma registry PROMs should also be suitable for collection by proxy and validated in different languages.(49)

Despite the barriers to PROM collection in trauma registries, there is a drive from policy makers to

address these challenges as patients experiences are required to drive quality improvements in trauma care.(50, 51)

Conclusion

Traumatic injury is a leading cause of disability which can have significant impact on people's quality of life and well-being.(1) Clinical outcomes provide a restricted perspective of recovery from traumatic injury and evidence demonstrates there is a high prevalence of problems related to mobility, self-care, usual activities, pain/discomfort, and anxiety/depression at 3-years post-injury.(2) Increased survival rates following traumatic injury have driven the need to improve understanding of the impact of trauma on symptoms and quality of life.(1) PROMs have an important role to capture these outcomes and quantify the patients' perspective. PROM data will be essential to inform further improvements in trauma care at an individual level and healthcare system level.(15) However, PROMs are currently underutilised in trauma populations.

This review has summarised the value of PROM use at individual and aggregate levels for trauma research, clinical practice and registries. Selection of PROMs for each of these uses requires clear rationale and thorough consideration of data collection methods, including practicalities/ logistics, burden to patients and training requirements.(49) Further consideration should be given to standardised approaches to the collection of PROMs to meet multiple stakeholder needs in an efficient way. Evaluation of such systems and iterative developments will be necessary. It is essential to include patients in the selection process to ensure the PROM is relevant and acceptable. Measurement properties of PROMs should also be considered in the context of the specific trauma population. However, the heterogeneity in types of traumatic injury and impact of injury on symptoms and quality of life presents challenges for selecting PROMs.

Author Contribution

The review concept was conceived by GT, AS, AR, CM, DK, AB and MC. GT conducted the searches, identified relevant papers, conducted the narrative synthesis and drafted the manuscript. AS, AR, CM, DK, AB and MC provided feedback on the manuscript. All authors read and approved the final manuscript.

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Table 1. Summary of the number of items, domains and example questions of the SF-36, HADS and EQ-5D.

PROM	Generic or condition-specific	Number of items	Domains	Example questions
SF-36	Generic	36	Physical functioning, role limitations-physical, bodily pain, general health, vitality, social functioning, role limitations-emotional and mental health	In general, would you say your health is: a) Excellent b) Very Good c) Good d) Fair e) Poor
HADS	Anxiety and depression	14	Anxiety, depression	I get sudden feelings of panic: 3 Very often indeed 2 Quite often 1 Not very often 0 Not at all
EQ-5D	Generic	5	Mobility, capacity for self-care, conduct of usual activities, pain/discomfort, anxiety/depression	MOBILITY: Choose one of these items / levels: i) I have no problems in walking about ii) I have slight problems in walking about iii) I have moderate problems in walking about

	iv) I have severe problems in walking about v) I am unable to walk about

EQ-5D: EuroQol 5-Dimentions; HADS: Hospital Anxiety and Depression Scale; PROM: Patient Reported Outcome Measure; SF-36: Short Form-36

Table 2. PROMs used in trauma research

Author (Year)	Study design (Country)	Trauma category	PROM	Overview
Spikman (2010)(52)	RCT (Netherlands)	TBI	Role Resumption List (RRL); Treatment Goal Attainment (TGA)	75 TBI patients were randomised to the intervention (multifaceted strategy training for executive dysfunction) or the control treatment (computerized cognitive function training). Assessment took place before, directly after, and 6 months post-treatment. The intervention group had significantly improved executive functioning compared to the controls.
Polinder (2007)(48)	Longitudinal study (Netherlands)	Major trauma	EuroQol 5-Dimensions (EQ-5D)	8,564 injury patients who had visited an emergency department were followed up at 2.5, 5, 9, and 24 months. Hospitalization, age and sex (females), type of injury (spinal cord injury, hip fracture, and lower extremity injury), and comorbidity were significant predictors of poor functioning in the long-term.

MacKenzie (2008)(53)	Retrospective cohort (USA)	Lower-limb trauma	Short Form- 36 (SF-36); Musculoskeletal Function Assessment (MFA); Revised Center for Epidemiologic Studies Depression Scale (CESD-R)	PROM data from 1,389 lower-limb trauma patients from either hospitals with a trauma centre (n=18) or hospitals without a trauma centre (n=51) were compared. Clinically meaningful improvements in physical functioning and overall vitality were found at one year after the injury for patients treated at hospitals with a trauma centre.
Waaler Bjørnelv (2012)(54)	Cost effectiveness (Norway)	Neck fractures	EuroQol 5-Dimensions (EQ-5D)	Cost-effectiveness was calculated for hemiarthroplasty (n=80) compared to internal fixation (n=86) for elderly patients with displaced femoral neck fractures. QALYs were calculated using EQ-5D. Over the 2-year period, patients treated with hemiarthroplasty gained 0.15-0.20 more QALYs than patients treated with internal fixation.

PROM: Patient Reported Outcome Measure; QALYs: Quality Adjusted Life Years; RCT: Randomised Controlled Trial; TBI: Traumatic Brain Injury; USA: United States of America

Table 3. Summary of systematic reviews reporting PROMs in trauma.

Author (year)	Trauma category	Number of studies included	Number of PROMs identified (n injury-specific PROMs)	Most commonly used PROM
Griffiths (2017)(17)	Burns	117	77 (6)	Short Form- 36 (SF-36); Burn-Specific Health Scale-Brief (BSHS-B); Brief Symptom Inventory
Jayakumar (2017)(19)	Upper extremity trauma	144	68 (9)	Not reported
Ologunde (2017)(20)	Facial trauma	21	12 (6)	Geriatric Oral Health Assessment Index; Nasal Obstruction Symptom Evaluation (NOSE)
Dacombe (2016)(16)	Hand and wrist trauma	30	9 (7)	Disabilities of the Arm, Shoulder and Hand (DASH); Patient-Rated Wrist Evaluation (PRWE)
Polinder (2015)(21)	Traumatic brain injury	49	18 (not reported)	Short Form- 36 (SF-36); Sickness Impact Profile (SIP); Pediatric Quality of Life Inventory (PedsQL)
Hoffman	Major trauma	34	38 (2)	Short Form- 36 (SF-36);

(2014)(18)	EuroQol 5-Dimensions (EQ-5D)

PROMs: Patient Reported Outcome Measures

Table 4. Trauma registries collecting PROMs.

Registry	Country	PROMs collected	Time point of PROMs collection	Method of PROMs collection
Victorian State Trauma Registry	Australia	Glasgow Outcome Sale-Extended (GOS-E); Short Form- 12 (SF-12); EuroQol 5-Dimensions (EQ-5D); Five-point Likert scale for disability; Numerical rating scale for pain; Return to work	6, 12 and 24 months	Telephone interview
Trauma Audit and Research Network	UK	EuroQol 5-Dimension- 5 Level (EQ5D-5L); Patient Reported Experience Measure; Return to work/ education; Glasgow Outcome Sale-Extended (GOS-E)	Baseline (as soon as possible post-injury) and 6 months	Post
Functional Outcomes and Recovery after Trauma Emergencies project	USA	Trauma Quality of Life Instrument; Short Form- 12 (SF-12); PTSD screening questionnaire; Return to work	6 and 12 months	Telephone interview

Burns Registry of Australia and New Zealand	Australia and New Zealand	Burn Specific Helath Scale-Brief (BSHS-B); Short Form- 36 (SF-36); Sickness Health Profile (SHP); Brief Fatigue Inventory (BFI); Itch questionnaire	1, 6, 12 and 24 months	Telephone or face-to-face interview or post

PROMs: Patient Reported Outcome Measures; PTSD: Posttraumatic Stress Disorder; UK: United Kingdom; USA: United States of America