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

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BACKGROUND: The aim of this scoping review is to identify and summarize patient-reported outcome measures (PROMs) that are being used to track long-term patient-reported outcomes (PROs) after injury and can potentially be included in trauma registries.

METHODS: Online databases were used to identify studies published between 2013 and 2019, from which we selected 747 articles that involved survivors of acute physical traumatic injury aged 18 years or older at time of injury and used PROMs to evaluate recovery between 6 months and 10 years postinjury. Data were extracted and summarized using descriptive statistics and a narrative synthesis of the results.

RESULTS: Most studies were observational, with relatively small sample sizes, and predominantly on traumatic brain injury or orthopedic patients. The number of PROs assessed per study varied from one to 12, for a total of 2052 PROs extracted, yielding 74 unique constructs (physical health, 25 [34%]; mental health, 27 [37%]; social health, 12 [16%]; cognitive health, 7 [10%]; and quality of life, 3 [4%]). These 74 constructs were assessed using 355 different PROMs. Mental health was the most frequently examined outcome domain followed by physical health. Health-related quality of life, which appeared in more than half of the studies (n = 401), was the most common PRO evaluated, followed by depressive symptoms. Physical health was the domain with the highest number of PROMs used (n = 157), and lower-extremity functionality was the PRO that contributed most PROMs (n = 33).

CONCLUSION: We identified a wide variety of PROMs available to track long-term PROs after injury in five different health domains: physical, mental, social, cognitive, and quality of life. However, efforts to fully understand the health outcomes of trauma patients remain inconsistent and insufficient. Defining PROs that should be prioritized and standardizing the PROMs to measure them will facilitate the incorporation of long-term outcomes in national registries to improve research and quality of care. (*J Trauma Acute Care Surg.* 2021;90: 891–900.

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Traumatic injury survivors often suffer from physical, emotional, cognitive, and financial consequences that can affect their lives, their families, and society for prolonged periods of time.[1–7] Seminal studies on long-term trauma outcomes in the United States have shown that deficits in physical, mental, and social health lead to poor quality of life, increased chronic disease, greater functional limitations, and failure to return to work.[4–13]

Although traumatic injuries have a significant negative impact on patients' long-term health and quality of life, there are currently no efforts to systematically collect long-term outcomes data in the United States, making it difficult to monitor recovery and identify opportunities for intervention to improve outcomes. Furthermore, there is no consensus on which data elements should be collected to be able to benchmark outcomes between institutions and injury types. This lack of data prompted the National Academies of Sciences, Engineering, and Medicine (NASEM) to call for a National Trauma Research Action Plan (NTRAP) in its 2016 report.[14] Two years later, the US Army Medical Research and Materiel Command funded a project to develop a NTRAP (under contract no. W81XWH-18-C-0179). One of the NTRAP aims is to define optimal metrics to assess long-term functional outcomes in injured patients following hospital discharge. This requires establishing a consensus that determines which patient-reported outcomes (PROs) are important to the trauma patient and should be prioritized, and which patient-reported outcome measures (PROMs) should be used to measure them.

According to the US Food and Drug Administration, a PRO is "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else," while PROMs are the tools or instruments used to measure PROs. These tools (PROMs) measure, in a standardized fashion, complex issues, such as health-related quality of life, functional status, symptoms and symptom burden, and health-related behaviors, thus providing an accurate and reliable assessment of PROs.[15] Defining optimal PROMs to track PROs and incorporating them into national trauma registries will allow researchers and clinicians to systematically assess the quality of trauma care, benchmark trauma centers, track patient improvement over time, implement and improve public health programs, and identify future research priorities.

However, at present, it is not clear which PROMs have been used in the literature to measure long-term PROs following traumatic injury, which constructs these PROMs have assessed, or which trauma populations these PROMs have helped evaluate. Further, there is currently no national consensus on which PROMs should be used to track long-term PROs after injury. To address this, we formulated a two-step plan: (1) Conduct a scoping review of the literature to systematically map the evidence on available PROMs to quantify long-term PROs after injury, as well as to identify any existing gaps in knowledge; and 2) use the results of the scoping review to inform a modified Delphi consensus process that aims to provide a proposed list of PROs/PROMs for inclusion in trauma registries. In the current article, we aim to present the results of the scoping review (first step), for which the following research question was formulated: What is known from the literature about PROMs that are being used to measure recovery and long-term outcomes after injury?

METHODS

Protocol and Registration

Our protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines and revised by the research team and members of the NTRAP Publications Committee for scientific content and consistency of data interpretation with previous NTRAP publications. The final protocol was published and made available online on May 28, 2020 in *Trauma Surgery & Acute Care Open* journal (https://tsaco.bmj.com/content/5/1/e000512).[16] The protocol was disseminated through the Coalition for National Trauma Research twitter account (@NatTrauma).

Eligibility Criteria

Studies were included in the analysis if they were written in English, published after 01-10-2013 (National Quality Forum landmark report on PROs in performance measurement), analyzed primary data, involved survivors of acute physical traumatic injury 18 years or older at the time of injury, and used PROMs to evaluate outcomes between 6 months and 10 years postinjury. We excluded studies that evaluated a mixed population of trauma and nontrauma patients, studies that examined chronic injuries occurring over a long period (e.g., stress fracture) and/or iatrogenic injuries, studies that only reported patient satisfaction or health care service as outcome measures, and studies that did not measure long-term PROs or did not report time of follow-up after injury. We included randomized control trials, cohort studies, case control studies, and cross-sectional studies. Narrative reviews, case series of less than 20 patients, case reports, conference presentations, and study protocols were excluded.

Information Sources

We searched for primary studies in PubMed and EMBASE. The search strategies were drafted in collaboration with an experienced librarian [Paul Bain] and further refined through team discussion. The final search strategy for MEDLINE can be found in Appendix B of the scoping review protocol (https://tsaco.bmj.com/content/5/1/e000512). The final search was executed on July 22, 2019, results were exported into EndNote, and duplicates were removed by team members. The electronic database search was supplemented by checking the citation lists of included studies and relevant reviews.

Selection of Sources of Evidence

Selection of sources of evidence was based on the inclusion/exclusion criteria, and carried out manually in two stages by six reviewers working in pairs using the Covidence online software:

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

Disagreements on study selection were resolved by consensus or by including a third reviewer.

Data Charting Process

A data-charting form was jointly developed by two reviewers (J.P.H.E. and S.O.) using Google Sheets to determine which variables to extract. The two reviewers independently charted the data, discussed the results and continuously updated the data-charting form in an iterative process. A data dictionary and training session were made available for the remaining reviewers.

All data specific to the review question and necessary for the narrative synthesis of outcomes was extracted. This included information on the study characteristics, population baseline characteristics, instruments used, and outcome measures. Data extraction was conducted independently by pairs of reviewers. One reviewer independently extracted the data from the included studies, and a second reviewer confirmed these findings. Disagreements were resolved by a third reviewer.

Data Items and Synthesis of Results

We abstracted data on article characteristics (e.g., first author of the article, year of publication, country of origin), population baseline characteristics (e.g., number of patients included in the study, injury type, injury location), PROs measured, and PROMs used. We used the following injury classification for the charting process: traumatic brain injury (TBI), spinal cord injury (SCI), orofacial trauma, whiplash injury, orthopedic trauma, multiple trauma, and burns. See Supplemental Digital Content (SDC, http://links.lww.com/TA/B911) 1 for the final version of the data-charting form.

General characteristics of the selected studies were summarized, and a narrative synthesis of the results was performed following the PRISMA-ScR guidelines. A conceptual model was developed, and studies grouped by health domains: physical health, mental health, social health, cognitive health, and quality

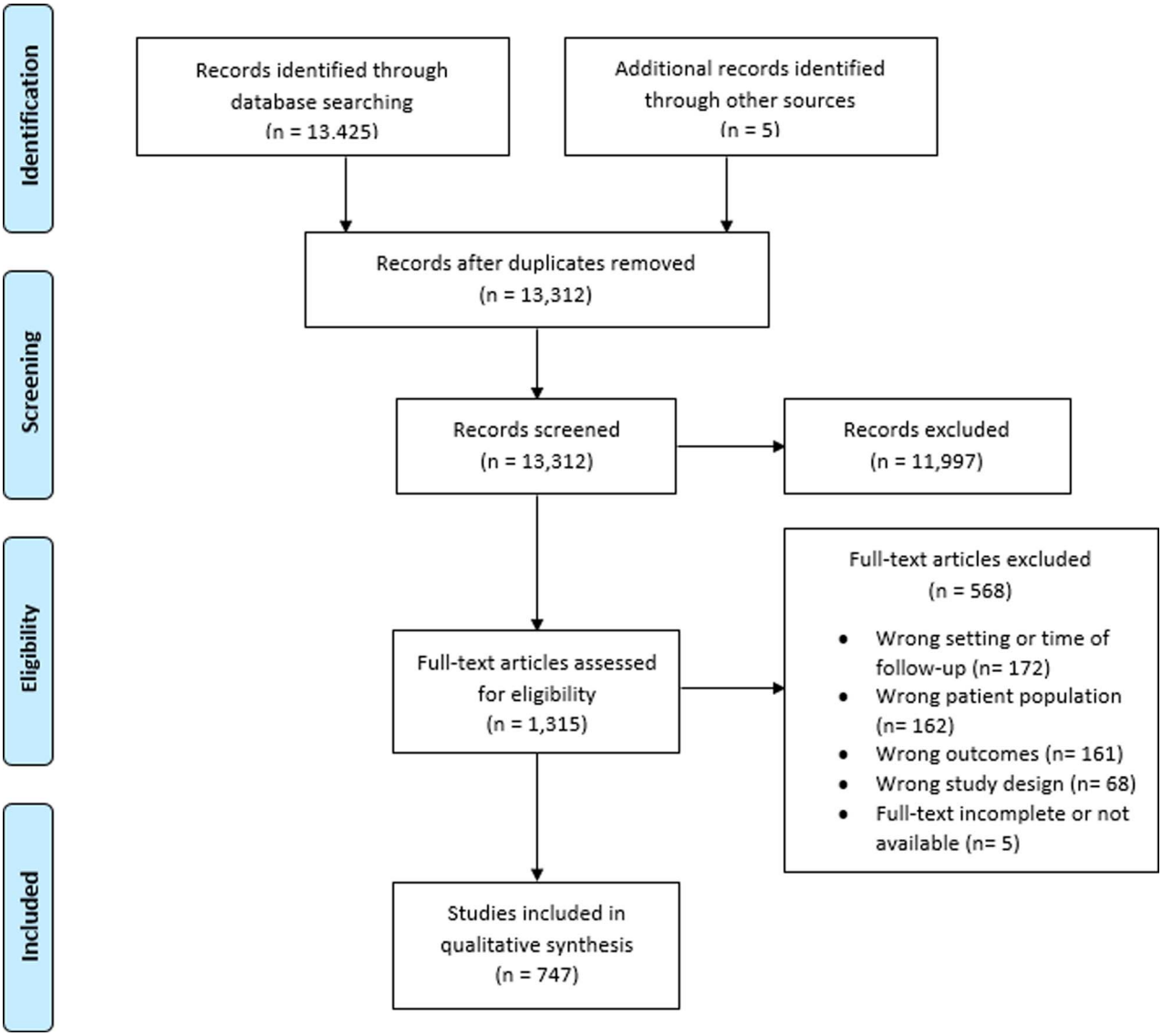

Figure 1. Flow diagram of studies for inclusion in a scoping review of long-term patient-reported outcome measures after injury.

of life. Within each domain, we identified the outcome measures/instruments used and identified gaps within the literature.

RESULTS

Search Results

The search returned 13,312 original articles for initial screening. Based on the inclusion and exclusion criteria, 747 studies were included. See PRISMA flow diagram (Fig. 1) for the step by step process of selection of sources of evidence. Studies from the United States, Australia, the Netherlands, and Canada comprise half of the sources of evidence. Most studies were observational, with relatively small sample sizes (83% of studies had 500 or fewer subjects), and predominantly focused on TBI and orthopedic patients. The included studies' country of origin, design, sample size, and injury characteristics are presented in Table 1.

TABLE 1. Study Characteristics

	N = 747
Year of publication	
2013–2014	223 (30%)
2015–2016	227 (30%)
2017–2019	297 (40%)
Country of origin	
United States	203 (27%)
Australia	83 (11%)
Netherlands	56 (8%)
Canada	40 (5%)
United Kingdom	38 (5%)
Other countries	327 (44%)
Study design	
Prospective cohort study	393 (54%)
Retrospective cohort study	139 (19%)
Cross-sectional study	126 (17%)
Randomized control trial	52 (7%)
Case-control study	22 (3%)
Number of study subjects included	
20–100	314 (42%)
101–500	305 (41%)
501–1000	67 (9%)
>1000	60 (8%)
Injury classification	
Orthopedic injury	253 (35%)
Traumatic brain injury	226 (31%)
Spinal cord injury	90 (13%)
Multiple trauma	76 (11%)
Burns	44 (6%)
Whiplash	19 (3%)
Orofacial	8 (1%)
Injury location (AIS region)	
Head and neck	234 (33%)
Face	11 (2%)
Torso and spine	111 (16%)
Extremities	231 (33%)
Multiple	114 (16%)
Racial/ethnic disparities	2 (0%)
Geriatric trauma	52 (7%)
Military trauma	41 (6%)
PROs assessed per article: range; median (IQR)	1–12; 2 (1–4)

Conceptual Model of Long-term PROs Postinjury

Patient-reported outcomes that were measured in the 747 studies were categorized based on the following domains: physical health, mental health, social health, cognitive health, and quality of life (Fig. 2). The multidirectional connectivity depicted in the diagram suggests that each health domain influences other domains, just as trauma affects different facets of a patient's life.

The number of PROs assessed per study varied from one to 12, with a total of 2,052 PROs extracted (physical health, 607 [30%]; mental health, 637 [31%]; social health; 188 [9%]; cognitive health, 110 [5%]; and quality of life, 509 [25%]), yielding 74 unique constructs (physical health, 25 [34%]; mental health, 27 [37%]; social health, 12 [16%]; cognitive health, 7 [10%]; and quality of life, 3 [4%]). These constructs were assessed using 355 different PROMs (SDC 2, http://links.lww.com/TA/B911), of which only 3.6% were trauma-specific PROMs. Table 2 provides a description of the frequency of appearance in the studies and number of PROMs associated with each of the 74 PROs by health domain. SDC 3 (http://links.lww.com/TA/B911) provides a definition for each of the 74 unique constructs identified.

Physical Health

Physical health PROs indicate the self-reported long-term condition of a patient's body after injury and take into consideration everything from persistent symptoms to functionality. Appearing 602 times in this review, the physical health outcome domain is the second most frequently examined outcome domain after mental health. A total of 25 unique physical health PROs were identified (Table 2). The physical health domain has the highest number of PROMs used (n = 156). The most used physical health outcomes examined patient-reported physical functioning, such as general mobility, general physical activity, activities of daily living, instrumental activities of daily living, extremity functionality, sexual functioning, urinary functioning, sensorimotor impairment, and bowel functioning. All injury classifications examined physical functioning outcomes. Burns and orthopedics were the two injury classifications that frequently evaluated chronic pain PROs. Chronic pain was a prevalent physical health domain, examined by four different PROs. Four PROs evaluated sleep, such as sleepiness, and are widely used in SCI and TBI populations. Three PROs were tailored to specific injuries, including postconcussive physical symptoms, SCI symptoms, and gastroenterological injury symptoms.

Mental Health

The mental health PROs captured in this review reflects the patient's self-reported state of mind and emotional wellness 6 months postinjury and beyond. Reigning as the most frequently examined outcome domain, mental health was evaluated by 27 different PROs. The outcome of depressive symptoms was the most frequently examined mental health PRO and appeared in more than a quarter of the articles included in this review. All injury classifications examined depressive symptoms and anxiety. Two outcomes specifically examined posttraumatic mental

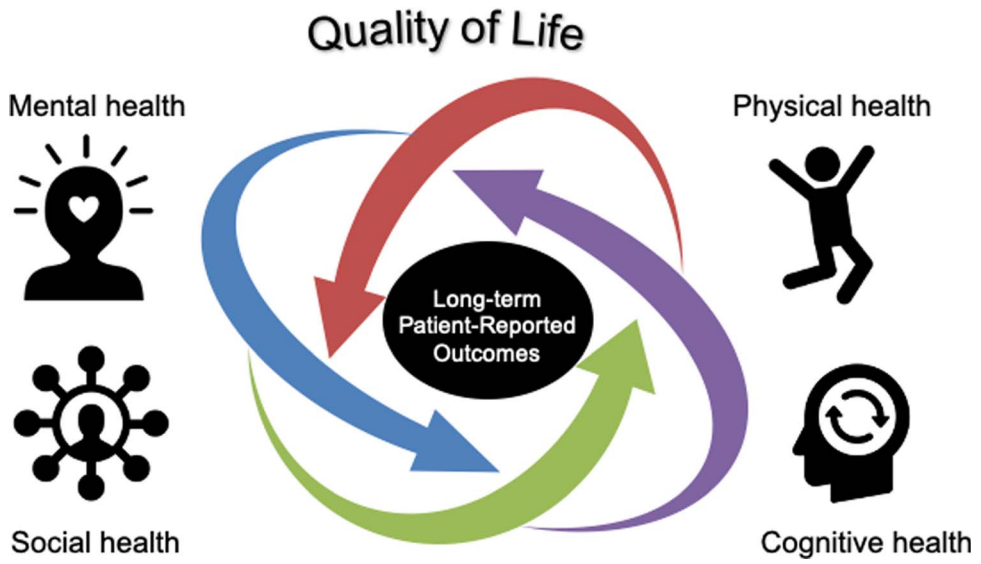

Figure 2. Conceptual model of long-term patient-reported outcomes after injury.

health functions: posttraumatic stress symptom spectrum and posttraumatic growth. As the most diverse domain, mental health includes a wide range of PROs, such as substance use, resilience, anger, and sexual satisfaction, among others. TBI classification used the widest array of mental health domains, followed by SCI, multiple trauma, orthopedic, and burns.

Social Health

Social health PROs depict a patient's self-reported interactions with his or her environment and their ability to carry out their role(s) within social settings, such as work, family, and community. A total of 12 outcomes describing social health were identified. The most frequently examined social outcome was general social functioning, which encompassed social participation and community integration. Seven outcomes specifically examined occupation-related functioning, such as return to preinjury work (which was used in all injury classifications), work productivity and performance, and job stability. Four measures examined other aspects of a patient's social life, including return to sports or leisure activities, relationship quality, spiritual well-being, and economic impact. Of note, the second and third most frequently evaluated PROs in this domain, return to preinjury work and work status, were not measured using a standardized PROM, but rather by one or two questions designed by the researchers.

Cognitive Health

Cognitive health PROs represent the patient's self-reported ability to clearly think, learn new things, remember, concentrate, and make decisions after injury. A total of seven cognitive PROs were identified. Outcomes evaluated were general cognitive functioning, postconcussion symptoms, executive functioning, memory complaints, mental fatigue, impulsivity, and concentration/attention. Postconcussion cognitive symptoms include a cluster of postminor head injury symptoms such as memory loss and inability to concentrate, irritability, and executive function impairment, which were separate from postconcussion physical symptoms, such as headache, sleep disturbance, and neck pain. Postconcussion symptoms were the most frequently assessed PRO in this domain, followed by general cognitive functioning. TBI classification covered all seven PROs.

Quality of Life

Quality of life PROs reflect a patient's self-reported global functioning. This domain included a combination of physical health, mental health, social health, and cognitive health. A total of three quality of life outcomes were identified. Health-related quality of life examined the impact of a patient's health status on their global functioning. Disease-specific quality of life examined a patient's global functioning impacted by a specific disease, injury, or symptom such as burns, TBI, and dizziness. Satisfaction with life was a quality of life outcome assessing a patient's general well-being, focused on mental and social functioning. Health-related quality of life was the most common PRO assessed in the literature (n = 401) and appeared in a majority of the included studies. All injury classifications contributed to examining health-related and disease-specific quality of life. Both health-related quality of life and disease-specific quality of life, along with lower extremity functionality from the physical health domain, were among the PROs with the highest number of associated PROMs.

Commonly Used PROMs and Research Gaps

Short-Form-12 and 36, EuroQoL Five-Dimension, Hospital Anxiety and Depression Scale, Disabilities of the Arm, Shoulder and Hand Score, Patient Health Questionnaire-9, posttraumatic stress disorder Checklist Civilian Version, Beck Depression Inventory, World Health Organization Quality of Life Scale, and PROMIS measures were the 10 PROMs more frequently used. Among them, PROMIS measures were those that measured the highest number of different PROs: eight.

TABLE 2. Patient-Reported Outcomes/Constructs by Health Domain

Health Domain	Subdomain	Patient-Reported Outcome/Construct	Frequency of Appearance in Studies	Injury Classification	No. Associated PROMs
Physical health (n = 607)	Physical functioning (n = 377)	Physical mobility/function	124	Burns, orofacial, ortho, multiple trauma, SCI, TBI, whiplash	8
		Upper extremity functionality	85	Burns, ortho	21
		Activities of daily living	73	Burns, ortho, multiple trauma, SCI, TBI	13
		Lower extremity functionality	41	Ortho, multiple trauma, TBI	33
		Sexual functioning	18	Ortho, SCI, TBI	11
		Physical activity	15	Burns, ortho, SCI	10
		Urinary functioning	8	ortho, SCI	2
		Instrumental activities of daily living	6	Burns, ortho, SCI, TBI	3
		Sensorimotor impairment	5	Orofacial, ortho, TBI	1
		Bowel functioning	2	Burns, ortho, SCI	1
	Pain (n = 125)	Pain (general)	110	Burns, orofacial, ortho, multiple trauma, SCI, TBI, whiplash	21
		Pain intensity	9	Burns, ortho, SCI, TBI	5
		Prescribed narcotic use	3	Burns, ortho	0
		Pain persistency	3	Burns, ortho	1
	Not applicable (n = 50)	General physical health	41	Burns, ortho, SCI, TBI	6
		New events	5	Ortho, SCI	0
		Health care utilization	2	multiple trauma, SCI	0
		Complications	2	multiple trauma	0
	Sleep (n = 38)	Sleep (general)	20	multiple trauma, SCI, TBI	4
		Fatigue	11	Burns, SCI, TBI	6
		Insomnia	5	SCI, TBI	3
		Sleepiness	2	SCI, TBI	1
	Injury-specific symptoms (n = 17)	Postconcussive physical symptoms	13	TBI	3
		GI symptoms	3	Nonspecific	0
		Spinal cord injury physical symptoms	1	SCI	1
Mental health (n = 638)	Not applicable (n = 637)	Depressive symptoms	202	Burns, orofacial, ortho, multiple trauma, SCI, TBI, whiplash	20
		Anxiety	117	Burns, orofacial, ortho, multiple trauma, SCI, TBI, whiplash	8
		Posttraumatic stress symptom spectrum	98	Burns, ortho, multiple trauma, SCI, TBI, whiplash	15
		Mental health (general)	34	Burns, ortho, multiple trauma, SCI, TBI	16
		Alcohol use	26	Burns, ortho, multiple trauma, SCI, TBI	4
		Pain catastrophizing	25	Orofacial, ortho, multiple trauma, SCI, TBI, whiplash	3
		Self-efficacy	15	Orofacial, ortho, multiple trauma, SCI, TBI, Whiplash	8
		Coping	15	Burns, ortho, multiple trauma, SCI, TBI, whiplash	13
		Fear avoidance	10	Ortho, multiple trauma, TBI, Whiplash	4
		Dispositional optimism/pessimism	10	Multiple trauma, SCI	2
		Resilience	8	Ortho, multiple trauma, SCI, TBI	4
		Illness perception	8	Orofacial, ortho, TBI	5
		Self-esteem	7	Burns, orofacial, SCI, TBI	3
		Self-awareness	7	TBI	2
		Personality change	7	Burns, ortho, TBI	2
		Anger	7	Ortho, multiple trauma, TBI, whiplash	3
		Behavior changes	7	Burns, TBI	7
		Sexual satisfaction	6	SCI, TBI	1
		Suicidal ideation/behavior	5	SCI, TBI	2

Continued next page

TABLE 2. *(Continued)*

Health Domain	Subdomain	Patient-Reported Outcome/Construct	Frequency of Appearance in Studies	Injury Classification	No. Associated PROMs
		Posttraumatic growth	5	Burns, multiple trauma, SCI	1
		Substance use	4	multiple trauma, TBI	3
		Subjective appraisal—appearance	4	Burns, orofacial, ortho, TBI	1
		Kinesiophobia	4	Ortho, whiplash	1
		Sense of coherence	3	Ortho, SCI, TBI	1
		Purpose in life	1	TBI	2
		Disability acceptance	1	TBI	1
		Agoraphobia	1	SCI	1
Social health (n = 188)	Occupation-related (n = 97)	Return to work	51	Burns, orofacial, ortho, multiple trauma, SCI, TBI, whiplash	0
		Work status	24	Ortho, SCI, TBI, whiplash	0
		Work role functioning	8	Nonspecific, ortho, whiplash	2
		Leave(s) of absence	6	Nonspecific, ortho, multiple trauma	0
		Work productivity and performance	5	Multiple trauma, SCI, TBI	5
		Employment stability	2	Multiple trauma, TBI	0
		Job satisfaction	1	Nonspecific	1
	Not applicable (n = 91)	Social functioning (general)	65	Burns, orofacial, ortho, multiple trauma, SCI, TBI	20
		Economic Impact	8	Ortho, TBI	2
		Return to sports/leisure activities	7	Ortho, SCI	5
		Relationship quality	7	Multiple trauma, SCI, TBI	2
		Spiritual well-being	4	SCI, TBI	3
Cognitive health (n = 110)	Not applicable (n = 110)	Postconcussion symptoms	45	TBI	4
		Cognitive functioning (general)	42	Ortho, SCI, TBI	16
		Executive functioning	9	TBI	4
		Memory complaints	5	TBI	4
		Mental fatigue	3	TBI	3
		Impulsivity	3	TBI	2
		Concentration/attention	3	TBI	2
Quality of life (n = 509)	Not applicable (n = 509)	Health-related quality of life	401	Burns, orofacial, ortho, multiple trauma, SCI, TBI, whiplash	30
		Disease-specific quality of life	69	Burns, orofacial, ortho, multiple trauma, SCI, TBI, whiplash	31
		Satisfaction with life	39	Burns, ortho, SCI, TBI	4

Figure 3 presents a synthesis of the main research gaps uncovered and calls to action of this scoping review.

DISCUSSION

In this comprehensive scoping review of the literature, we identified 747 primary studies examining long-term PROMs after injury published between 2013 and 2019. Our findings indicated that most of the evidence on this topic focuses on specific injury types such as TBI or orthopedic injuries, and that there is a paucity of research focusing on other injury types or mechanisms, such as facial trauma, multiple trauma, or burns. Although we found an important diversity of PROs, there were significant imbalances in the frequency of evaluation of these PROs, the number of associated PROMs, and the populations in which they were used. These imbalances occurred both within and between health domains. Specifically, social and cognitive health domains were underrepresented in both the number of PROs and the frequency of assessment. We also found that there were almost five times more PROMs than constructs measured, many which were neither designed nor validated to address the needs of the trauma population. This review builds on and enhances the findings of previous reports that recognize the lack of standardization and trauma-specific PROMs as barriers to better understand long-term outcomes after injury and their utility as quality improvement measures.[17,18] Despite the increasing support for use of PROMs in the literature, the evaluation of patient-reported health outcomes in trauma remains inconsistent and insufficient.

Most of the studies captured in this scoping review were observational; only 7% were randomized controlled trials. As we transition to using PROs as measures for quality-of-care improvement in trauma, it is important that we design studies with greater methodological rigor to test interventions where the outcome is a PRO. This becomes particularly relevant in comparative effectiveness and patient-centered outcomes research.

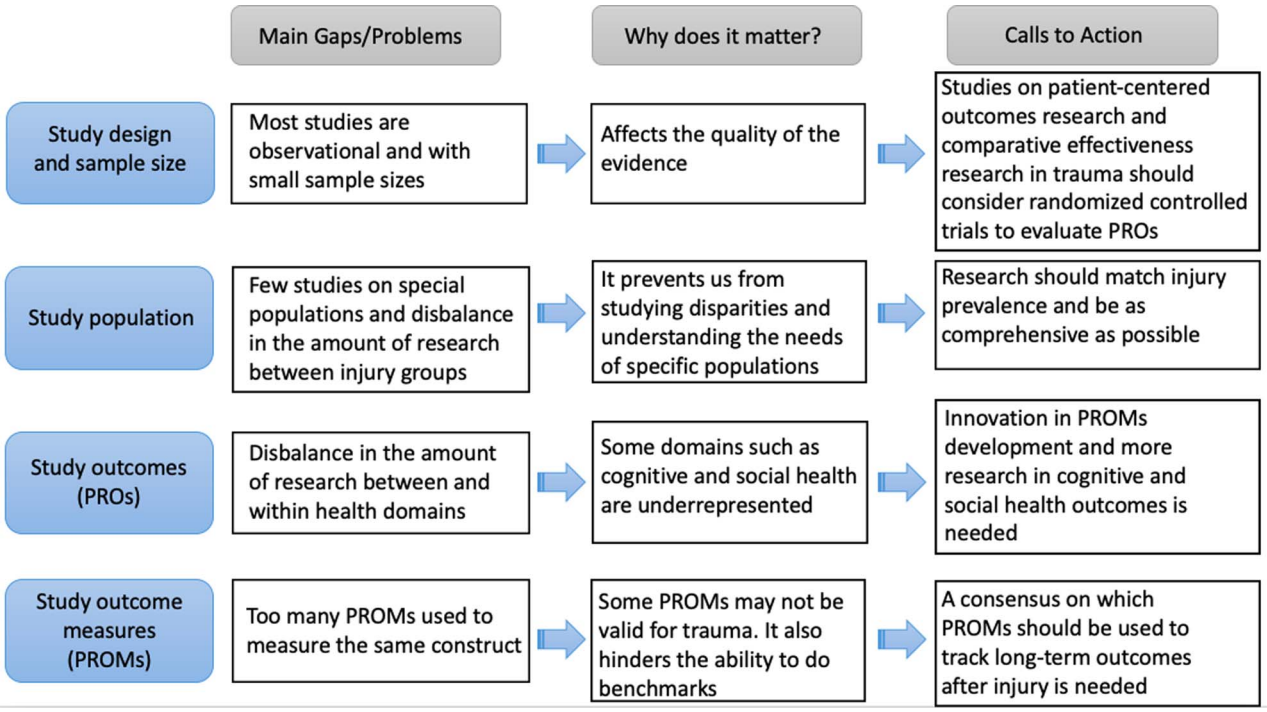

Figure 3. Gaps and calls to action.

Randomized-controlled trials, in addition to being at the top of the evidence pyramid, also have available reporting standards[19] that will enable accurate interpretation of evidence to inform patient choice, aid clinical decision making, and inform health policy.

According to the results, about two thirds of the research published in long-term outcomes after injury focuses on TBI and orthopedic injuries, which is consistent with previous reports.[18] Although the head and extremities are the most commonly affected AIS body regions after a traumatic injury in the United States,[20] there are other injury groups where the amount of published research does not match the prevalence of the injury. For instance, according to the 2016 annual report from the National Trauma Data Bank,[20] 25% of injured patients in the United States suffered from an injury to the face, yet only 2% (11/747) of articles included in this review analyzed PROs in facial trauma. One of the reasons for this mismatch may be that facial injuries are often classified as minor injuries with a very low complication/mortality rate, and, thus, long-term outcomes may be overlooked. Whereas long-term outcomes after injury are not necessarily associated with the severity of the injury or the likelihood of dying[4,21]; it is therefore important to measure the physical, social and mental health consequences across all injuries regardless of their severity.

While physical health is often the most salient outcome after injury, the literature has recognized that long-term functional outcomes need to be assessed across all facets in the model. For example, mental health outcomes were just as commonly measured as physical health outcomes, and social health outcomes were as prevalent as cognitive health outcomes. By categorizing long-term PROs postinjury, more targeted instruments and interventions can be developed to accurately measure and address them. Each facet of the long-term functional outcome model is interlinked; each facet affects and is affected by each of the other health domains. It is also evident that social health and cognitive health outcomes are not as commonly assessed as their physical and mental counterparts. More development and usage of social, cognitive, and quality of life outcomes are needed to ensure a holistic approach to providing care to trauma patients.

The dearth of cognitive PRO appearance can be explained by the fact that cognitive functioning is traditionally and more commonly assessed through performance-based, objective testing. In the process of screening articles, several studies in the cognitive outcome domain were excluded due to their use of physician-administered testing, such as the Timed Up and Go test. Long-term postinjury cognitive PROs thus remain an area for more research.

Occupation-related outcomes accounted for more than half of the outcomes and appearances in the social health domain. Yet only three out of seven of these outcomes were evaluated using a standardized PROM. Occupation-related PROMs that have been used in trauma focus on constructs such as work role functioning, work productivity and performance, and job satisfaction. However, these PROMs fail to include other important occupation-related outcomes such as return to work, work status, leave(s) of absence and employment stability, which may be taken into consideration when selecting PROMs for the social health domain.

Within each facet of the long-term PRO model, there is a wide range of outcomes being measured. For example, in addition to commonly used outcomes such as depressive symptoms, anxiety, and posttraumatic stress symptom spectrum; alcohol use, pain catastrophizing, and disability perception are gaining recognition as mental health outcomes. Combined, these outcomes provide valuable information on a patient's functional status after injury.

Among the main injury classifications, TBI and SCI were the most ubiquitous in PRO studies. These two classifications, along with other classifications such as burns and orthopedic, also generated injury-specific PROs and PROMs in the physical health and quality of life domains. This is important to note, as more frequent use of trauma-specific measures would help improve the study of long-term trauma outcomes.

We found a significant number of PROMs that were used to track long-term outcomes after injury and that were used in a diverse array of injury classifications. Frequently assessed outcomes, such as pain or depressive symptoms, were measured with at least 20 different PROMs. Measuring the same construct with different PROMs hinders opportunities to aggregate data across studies or benchmarks for quality improvement. Further, some of these PROMs may not have been designed for or validated in trauma patients. We also found that some special populations were underrepresented both in the number of studies and in the PROMs specific to them. For example, only 2/747 articles focused on studying racial/ethnic disparities after injury, and only a handful of PROMs used in geriatric trauma patients were specifically designed for older adults. This despite the considerable number of articles that studied long-term PROs in geriatric trauma patients. In addition, with an increasing number of studies suggesting the female sex and gender-, racial-, ethnic-minority groups are associated with worse trauma outcomes, it is imperative that PROs and PROMs are applicable to a wide variety of demographics. Yet, PROs and PROMs are often tailored to a historically privileged population. For instance, sexual dysfunction and satisfaction PROMs often inquire only about erectile dysfunction, but questions regarding the female equivalence should also be provided. Recognizing, addressing, and correcting the use of PROMs that are inherently biased is a step toward eliminating disparities in our health care system.

Translating research into pragmatic practices, the NTRAP collaboration aims to develop and operationalize a suite of long-term PROs and related PROMs for trauma patients. It is no easy task; trauma is a diverse field with arrays of injury, classification, mechanism, severity, and patient populations. While a broad, generalized set of PROs provides ease in implementation, being broad may fail to detect debilitating problems specific to certain injuries. On the other hand, a detailed, exhaustive set would be a logistical challenge and not user-friendly. Rather than a dichotomous swing between too broad and too narrow, another option is to develop a generalizable set of PROs/PROMs pertinent to all trauma patients with supplemental sets tailored for specific injuries. Additional expertise, including the input of trauma patients, is warranted in developing a robust, user-friendly, informative list of long-term postinjury PROs/PROMs. This list should be comprised of modern, validated psychometric measures that are feasible and usable in both research and clinical contexts. This a common set of data elements and measurement tools will facilitate the improvement of quality and comparability of research on PROs/PROMs. This will be the goal of the modified Delphi consensus process of the NTRAP that follows this scoping review (the second step of this process that is underway).

This scoping review is not without limitations and must be interpreted in the context of its design. To make our review more feasible, we were only able to include studies published after the 2013 National Quality Forum report on PROs, which means we did not capture PROs and PROMs evaluated before that date. Trauma is a heterogeneous population, and the characteristics of patients and injuries may differ significantly between and within studies, affecting the generalizability of general findings to certain subgroups. The lack of granularity in this information in some studies plus the lack of standardization to measure some of these characteristics (e.g., injury severity), was a barrier to performing subgroup analyzes. Furthermore, the results of this review may not be generalizable to long-term trauma outcomes in general, as this review only captures "patient-reported outcomes." Other forms of outcome tracking, such as performance-based tests, clinician evaluations, clinician-reported outcomes, or passive sensing of health outcomes via electronic devices were not considered.

CONCLUSIONS

We identified a wide variety of PROs and PROMs available to track long-term outcomes after injury in five different health domains: physical, mental, social, cognitive, and quality of life. Nonetheless, efforts to fully understand the health outcomes of trauma patients remain inconsistent and insufficient, specifically for certain injury populations and health outcome domains. The results of this review are being used to inform a modified Delphi consensus process that aims to provide a proposed list of PROs/PROMs for inclusion in trauma registries. This consensus is an important step in the development of the NTRAP, which will facilitate the benchmarking of outcomes across institutions and injury types to improve quality and advance the field of injury care.

AUTHORSHIP

J.P.H.E., S.Y.O., S.D., A.T., C.P.O., M.C.A., A.R., M.B.J., M.A.A., and E.R. performed the literature search and data extraction. J.P.H.E., S.Y.O., E.R., M.P.J., D.N., M.A.P., E.B., A.H.H., and the NTRAP Investigators Group contributed to the study design. J.P.H.E. and S.Y.O. conducted the data analysis. All authors participated in the article drafting or provided critical revision.

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