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Erratum
The initial publication of this article included a bar graph with an incorrectly scaled axis (Figure 2; p. 35). The PDF currently available for download was last updated on July 18, 2016, with a revised Figure 2 that accurately reflects the corresponding data detailed in the Results section.
Patient- and Family-Identified Problems of Traumatic Brain Injury: Value and Utility of a Target Outcome Approach to Identifying the Worst Problems

Laraine Winter, PhD,1,2 Helene J. Moriarty, PhD, RN,1,3 Catherine V. Piersol, PhD, OTR/L,4 Tracey Vause-Earland, OTR/L,4 Keith Robinson, MD,5,6 Brian Newhart, MSW5

1Philadelphia Research and Education Foundation, Corporal Michael J. Crescenz Veterans Affairs Medical Center, Philadelphia, PA
2Nursing Service, Corporal Michael J. Crescenz Veterans Affairs Medical Center, Philadelphia, PA
3Villanova University College of Nursing, Villanova, PA
4Department of Occupational Therapy, School of Health Professions, Thomas Jefferson University, Philadelphia, PA
5Rehabilitation Medicine Service, Polytrauma Network Site for Veterans Integrated Service Network-4, Corporal Michael J. Crescenz Veterans Affairs Medical Center, Philadelphia, PA
6Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

Purpose

This study aimed to identify the sequelae of traumatic brain injury (TBI) that are most troubling to veterans with TBI and their families and identify veteran-family differences in content and ranking. Instead of standardized measures of symptom frequency or severity, which may be insensitive to change or intervention effects, we used a target outcome measure for veterans with TBI and their key family members, which elicited open-ended reports concerning the three most serious TBI-related problems. This was followed by Likert-scaled ratings of difficulty in managing the problem.

Methods

In this cross-sectional study, interviews were conducted in veterans’ homes. Participants included 83 veterans with TBI diagnosed at a Veterans Affairs medical rehabilitation service and a key family member of each veteran. We utilized open-ended questions to determine the problems caused by TBI within the last month. Sociodemographic characteristics of veterans and family members, and veterans’ military and medical characteristics were collected. A coding scheme was developed to categorize open-ended responses.

Results

Families identified nearly twice as many categories of problems as did veterans, and veterans and families ranked problem categories very differently. Veterans ranked cognitive and physical problems worst; families ranked emotional and interpersonal problems worst.

Conclusions

Easily administered open-ended questions about the most troubling TBI-related problems yield novel insights and reveal important veteran-family discrepancies. (J Patient-Centered Res Rev. 2016;3:30-39.)

Keywords

traumatic brain injury; veterans; families; caregiving; measurement; patient-centered outcomes

Traumatic brain injury (TBI) has affected 321,454 service members from 2000 to 2014.1 Common TBI sequelae encompass poor memory, executive dysfunction, problems in mood and interpersonal behavior, physical functioning limitations, sleep disturbances, pain, tinnitus, photosensitivity, excessive emotionality and disturbances in behavior.2-6 Because the brain controls behavior, functioning and mood, TBI may produce many other symptoms and limitations, some unpredictable and idiosyncratic.

TBI-related problems and deficits in tasks and activities are commonly measured using standardized scales. These tasks and activities are usually grouped into subscales, categories or domains for analysis, generally corresponding to cognitive, interpersonal, emotional and physical limitations. In most cases, the groupings are defined by the investigators on a conceptual basis.7-12 In a few cases, the groupings have
been determined empirically through data reduction procedures such as factor analysis.\textsuperscript{13-15}

Although these functional rating scales possess good psychometric properties, the wide breadth of functional problems they encompass may make it difficult to document change or the effect of an intervention. The impact of a targeted intervention may be difficult to detect using a measure that encompasses a broad range of problems but may not contain the patient’s most important symptoms or complaints.\textsuperscript{16} Even if it does include these symptoms or complaints, they may not be adequately represented in the total score. This raises the risk of type II error (false negatives, i.e. the failure to reject a false negative hypothesis).\textsuperscript{17}

To address this problem, a target outcome (or target complaints) approach has been employed in psychotherapeutic, psychopharmacologic and behavior management trials to capture treatment effects on behavior, functioning and emotions.\textsuperscript{16,18-20} In a target outcome approach, patients (and/or their family caregivers) are asked an open-ended question about the most serious problem the condition causes. In Gitlin et al.’s studies,\textsuperscript{18,19} participants also used a Likert-scaled response format to rate how difficult it was to manage that problem. At follow-up, a blinded interviewer read the target problems participants had given at baseline and asked them to rate their current difficulty managing the problem utilizing a Likert scale\textsuperscript{18,19} or to rate the amount of change.\textsuperscript{16} This process was then used to identify the second and third most serious problems and their rated difficulty. This measurement approach therefore elicits both qualitative (responses to the open-ended questions) and quantitative data (Likert-scale ratings of difficulty managing the problem).

Target outcomes would seem an ideal measure for research in brain injury, which may produce an extremely wide array of sequelae. In addition, because most TBI research has studied moderate to severe TBI, a target outcome approach may illuminate problems experienced among mild TBI patients, less often studied than those with more severe injuries. Because this approach can be used with key family members (as can many standardized scales), it identifies the problems most troubling to them and therefore allows comparisons between reports from patients with TBI and their family members.

Target outcomes are also patient-centered outcomes, defined as those meaningful and important to patients and family members. Patient-centered outcomes research has been advocated since passage of the Affordable Care Act of 2009, which established the Patient-Centered Outcomes Research Institute.\textsuperscript{21,22} Winter and colleagues used this approach in a study of veterans with TBI and their key family members as part of a larger randomized control trial that evaluated an innovative in-home, family-inclusive program for veterans with TBI, the Veterans’ In-home Program (VIP).\textsuperscript{23} Quantitative data from the target outcomes (i.e. the Likert-scaled ratings of difficulty managing each problem identified by participants) served as an outcome in that trial. Veterans’ difficulty ratings in managing the outcomes — the quantitative portion of the target outcome questions — showed an effect of the VIP intervention, confirming this approach’s ability to detect intervention effects.

The investigation presented herein used only the open-ended reports about the most troubling TBI problems identified by veterans with TBI and family members in their own words. It compared responses from veterans and their key family members for both content and relative rankings. Data reported in this paper were collected during the baseline interviews.

**METHODS**

**Participants**

The study design was cross-sectional. Participants were 83 veterans with a TBI diagnosis, recruited from a medical rehabilitation service, and a family member selected by the veteran. All veteran participants had been diagnosed with TBI by clinical staff at the medical rehabilitation service using the Veterans Health Administration’s Polytrauma System of Care criteria for diagnosing TBI.\textsuperscript{24} Additional inclusion criteria were being postdeployment from the Vietnam War era to the present; having the ability to speak English; and having a family member or partner actively involved in his or her life, living with him or her or within close proximity (within 30 minutes transportation time) and willing to participate in the study. Exclusion criteria were veterans at high risk for violence as judged by the clinical team of the medical rehabilitation service.

Veterans were recruited through an institutional review board (IRB)-approved letter of invitation sent to medical rehabilitation service patients. Letters were followed up
with a phone call, which confirmed veterans’ eligibility for the study and elicited their willingness to participate.

**Measures**

**Sociodemographic Characteristics:** We elicited veterans’ and family members’ age, gender, race, Hispanic background, years of education, marital status, number of children, household size, employment status and financial well-being (defined as difficulty paying for basics like food).

**Injury, Comorbidity and Military Characteristics:** Retrieved from the VA’s Computerized Patient Record System (CPRS), these data included veterans’ war cohort, number of TBIs, number of years since first and most recent TBI, source of injury (blast, mechanical or both) and comorbidities (posttraumatic stress disorder, depression, pain, tinnitus and photosensitivity). In addition, severity level was determined through a review of CPRS by the medical director of the medical rehabilitation service, a physiatrist with expertise in TBI who reviewed the cases to assess TBI severity level using published criteria.

**Target Outcomes:** Veterans and key family members identified up to three problems they attributed to their TBI, experienced within the last month or so. The question posed to both veteran and family member was “What is the #1 problem TBI has been causing for you within the last month?” For the first identified problem, the participant then rated how difficult it was to manage the problem on a five-point Likert scale from 0 (not at all difficult) to 4 (extremely difficult). After the first problem was identified and rated for difficulty, the participant was asked to identify the next most troubling TBI-related problem and rate its difficulty, and finally the third most troubling problem and Likert rating.

**Procedure**

The study was approved by the IRB of the study site. Veterans and family members were interviewed in their home on the same day. The two interviews were conducted separately, outside the hearing of the other, to maintain independent responses.

**Data Analysis**

The research questions were designed to determine 1) the most serious problems that veterans with TBI and their family members experience, and 2) whether those identified by veterans differed from those identified by family members in content and ranking.

**Coding Open-Ended Reports of TBI-Related Problems:** A coding system was developed by two investigators (L.W. and H.M.) for the open-ended responses to the target outcome questions using the first 40 cases. Categories were defined to be broad enough to encompass similar concepts but narrow enough to recognize potentially important distinctions. For example, memory problems were distinct from executive function problems (e.g. organization, planning, poor judgment), the latter of which were grouped together. Several categories of physical problems were distinguished. Sensory problems encompassed tinnitus and sensitivity to light. Pain included headache and orthopedic pain. Instrumental activities of daily living (IADL) were limited to problems with specific IADLs (e.g. meal preparation, driving or using public transportation) and were distinguished from physical problems such as poor self-care (e.g. not eating healthy food, not wanting to shower). This coding system produced 22 categories. The two investigators coded all responses independently. Inter-rater agreement was 94.7%. Differences were resolved by consensus.

**Rankings of TBI-Related Problems and Ratings of Difficulty in Managing:** Mean ranking was calculated for each type of problem by assigning a “3” to problems identified as Problem #1, a “2” to the second most difficult problem, and a “1” to the problems reported for the third problem. For problems that the participant did not mention at all, a value of “0” was assigned for that problem category. Rankings for each type of problem therefore ranged from 0 to 3. Higher values indicated more highly ranked problems.

**Quantitative Data Analysis (Comparison of Problem Rankings by Veterans vs. Family):** To compare problem categories between veterans versus their family members, the use of 22 categories would pose an unacceptably high risk of spurious positives. Therefore, the 22 categories were grouped into cognitive, physical, emotional and interpersonal problems — the four categories used in most research on TBI-related problems. Distributions of summed rankings and their residuals were found to be reasonably normal. Therefore, ordinary least squares assumptions
were not violated. To examine differences between problem category types, rater (veteran vs. family) and their interaction, the summed rankings served as within-subjects factors in a repeated-measures analysis of variance (ANOVA). Problem category type and veteran versus family were between-subjects factors, and their main effects and interactions were evaluated.

**Identification of Possible Covariates:** Associations of the problem category rankings with sociodemographic variables, TBI severity and years since injury were tested. Pearson product moment correlation was used when the variables were normally distributed (e.g. age), Spearman’s rho when a variable’s distribution was skewed (TBI severity, years since TBI) and t-tests when one variable was dichotomous (e.g. sex). No associations were found between category rankings and any of these variables (P>0.05). Therefore, none were used as covariates in the ANOVAs.

**RESULTS**

**Sample Characteristics**

Table 1 presents sociodemographic characteristics of the veterans with TBI and their family members. Veterans had a mean age of approximately 40. Most were white; nearly one-third were black. Most family members were spouses or partners. Approximately one-third of veterans were employed compared with nearly two-thirds of family members.

Most TBIs were mild (Table 2). The wide range in time since most recent TBI injury was especially noteworthy — ranging from 1 to 45 years (for a Vietnam War veteran). However, all TBI evaluations and diagnoses were recently obtained. This reflects the many long-standing TBIs that have only recently been diagnosed, a result of increased awareness of TBI by health care providers and the VA's policy of routine screening for TBI in veterans of the wars in Iraq (Operation Iraqi Freedom [OIF]) and Afghanistan (Operation Enduring Freedom [OEF]). Most participants were OIF veterans, followed by OEF veterans, and 10.5% had served in both wars. Three-quarters of subjects had suffered a mechanical TBI, the most common cause being vehicular accidents. More than half had experienced blast-related injuries, and one-third had experienced both blast and mechanical injuries. More than one-third had experienced more than four TBIs. Most had a current posttraumatic stress disorder diagnosis and more than half a current depressive disorder. Approximately two-thirds reported pain, 25.0% tinnitus and 20.9% photosensitivity.

**Content and Ranking of TBI-Related Problems by Patients and Family Members**

Veterans’ responses to the question “What is the #1 (#2, #3) problem that TBI has caused in the last month?” required 12 coded categories. To capture family members’ responses, 10 additional categories (self-care [e.g. personal hygiene], emotional numbness, socially inappropriate behavior or excessive emotionality [aside from depression or anger], spending too much...
money, obsessive behaviors [e.g. hoarding], drinking problems, social withdrawal, low libido, poor appetite and driving problems) were required. By contrast, all types of problems mentioned by veterans also were mentioned by at least one family member. Table 3 presents the 22 TBI-related problem categories and their rankings by veterans and key family members.

Examination of Figure 1 shows that mean rankings of problem types were very different for veterans and family members. Memory problems and executive dysfunction were ranked highest by both veterans and their family member, although veterans ranked them much higher than did family members; however, anger and other emotional and interpersonal problems were ranked much higher by families than by veterans. Indeed, no veterans mentioned emotional numbness, excessive emotionality, obsessive behaviors, social withdrawal or several other types of behavior problems.

To compare problem type rankings statistically, the 22 problem codes were grouped into cognitive, physical, emotional and interpersonal categories. Rankings of items in each category were summed, and a 4 (categories) × 2 (veterans vs. family members) repeated-measures ANOVA was computed. No main effect for veteran versus family member was found (F[3,80]=1.96, P=0.165, eta²=0.023), but a main effect was revealed for problem categories (F[3,80]=61.24, P<0.001, eta²=0.697) as well as a significant interaction between rater (veteran, family member) and problem category (F[3,80]=14.902, P=0.001, eta²=0.358).

To interpret the interaction effect, post hoc t-tests comparing veteran to family member rankings were conducted for each problem type. These analyses revealed a reversal of direction of veteran-family difference for different TBI-related problems. Whereas veterans ranked cognitive and physical problems as worse (compared to family member rankings), family members ranked emotional and interpersonal problems worse than did veterans (Figure 2). Large differences, in opposite directions, between veteran and family were found for cognitive (veteran mean: 2.72, SD: 1.48; family mean: 1.75, SD: 1.54; t[82]=4.244, P<0.001) and emotional problems (veteran mean: 0.73, SD: 1.08; family mean: 1.73, SD: 1.64; t[82]=5.00, P<0.001). Smaller, though still significant,
differences were revealed for physical (veteran mean: 1.64, SD: 1.66; family mean: 1.10, SD: 1.31; \( t[82]=2.563, P=0.012 \)) and interpersonal problems (veteran mean: 0.31, SD: 0.75; family mean: 0.55, SD: 0.98; \( t[82]=2.017, P=0.047 \)). Post hoc t-tests therefore were conducted on all pairs of problem categories. Cognitive problems (mean: 4.47, SD: 0.24) were ranked significantly higher than physical (mean: 2.73, SD: 2.29; \( t[82]=4.28, P<0.001 \)), emotional (mean: 2.47, SD: 2.10; \( t[82]=5.36, P<0.001 \)) and interpersonal problems (mean: 0.87, SD: 1.36; \( t[82]=12.45, P<0.001 \)). Physical problems were ranked higher than interpersonal problems (\( t[82]=6.02, P<0.001 \)) but were not different from emotional problems (\( t[82]=0.636, P=0.527 \)), and emotional problems also ranked higher than interpersonal problems (\( t[82]=5.42, P<0.001 \)).

DISCUSSION
This study used target outcomes to identify the most serious problems caused by TBI as rated by veterans and their key family members and to compare content and rankings between groups. Findings showed that veterans and family members differed markedly in both the number of target problems they named and their rankings of these problem types. While confirming many veteran-family differences reported in copious research conducted with standardized instruments,\textsuperscript{10,11} target outcome questioning revealed additional insights. Applying the same criteria to defining categories of problems, many more categories were needed for family members’ identified problems — 22 vs. 12 for veterans. This highlights the wide range of TBI-related difficulties that families observe or experience and underscores the value of their observations. Using the ranking scores as dependent variables also revealed more veteran-family differences in types of problems than any single study based on standardized scales has shown. These findings confirm target outcomes as a practical measurement approach for TBI, one able to distinguish and detect differences that more conventional scales may not in a condition that may produce a vast and idiosyncratic array of symptoms and limitations.

Figure 1. Rankings of traumatic brain injury-related problems by veterans and family members.

Figure 2. Mean rankings (on a 0–3 scale) of four types of traumatic brain injury (TBI)-related problems by veterans and their key family members. Scale: 3 = worst TBI-related problem; 2 = second worst problem; 1 = third worst problem; 0 = not mentioned as a problem. Ranks are summed within each category, forming ratio-scaled variables.
Although standardized scales have the incontrovertible advantage of presenting problems that patients may not think of on their own, we found that the target outcome questions captured some problems not included on standardized scales. The target outcome questions, with their closed-ended difficulty rating (e.g. “How hard is it for you to manage this problem?” with Likert scale response), also allow investigators to quantify the effects of a treatment that targets the problems most important to the patient — as opposed to measuring a broad range of possible TBI problems derived from previous samples of patients, of which many may not trouble the veteran or family. A combination of standardized scales and target outcomes may present the optimal approach for assessing the sequelae from injury to the organ that controls emotions, cognition, functioning and behavior.

Inclusion of patient- and family-centered outcomes increases the relevance of research for participants and may speed translation of findings. Soliciting patient and family views on outcomes most important to them can help focus interventions to address the problems of greatest concern and may improve adherence to treatment regimen. Investigators usually select outcomes on the basis of their psychometric properties, theories, previous research and/or clinical experience, but seldom do they represent actively solicited

Table 3. TBI-related problems as rated by veterans with TBI, key family members

<table>
<thead>
<tr>
<th>Problem identified</th>
<th>Mean ranking*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Veterans</td>
</tr>
<tr>
<td>Memory problems</td>
<td>1.88</td>
</tr>
<tr>
<td>Executive function (organization, focus, attention, concentration) problems</td>
<td>0.71</td>
</tr>
<tr>
<td>Pain</td>
<td>0.71</td>
</tr>
<tr>
<td>Anger/irritability/moodiness/argumentativeness</td>
<td>0.45</td>
</tr>
<tr>
<td>Other physical problems (dizziness, loss of dexterity, seizures, low energy)</td>
<td>0.33</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>0.31</td>
</tr>
<tr>
<td>Relationship/communication issues</td>
<td>0.31</td>
</tr>
<tr>
<td>Sensory problems (tinnitus, sensitivity to light)</td>
<td>0.27</td>
</tr>
<tr>
<td>Depression/stress/anxiety/ worry/poor self-esteem</td>
<td>0.25</td>
</tr>
<tr>
<td>Speech (anomia and aphasia)</td>
<td>0.13</td>
</tr>
<tr>
<td>Poor motivation, apathy, poor initiation</td>
<td>0.04</td>
</tr>
<tr>
<td>IADLs (specific activities of daily living mentioned)</td>
<td>0.02</td>
</tr>
<tr>
<td>Social withdrawal from family, friends, activities/inability to care for children/marital infidelity</td>
<td>0.0</td>
</tr>
<tr>
<td>Socially inappropriate behavior/excessive emotionality/loss of control over emotions</td>
<td>0.0</td>
</tr>
<tr>
<td>Poor self-care (poor hygiene [not bathing], bad eating habits)</td>
<td>0.0</td>
</tr>
<tr>
<td>Obsessiveness (OCD, obsessive need for sameness, need to control others, hoarding)</td>
<td>0.0</td>
</tr>
<tr>
<td>Emotional numbness/lack of emotional expressiveness or compassion</td>
<td>0.0</td>
</tr>
<tr>
<td>Drinking problems</td>
<td>0.0</td>
</tr>
<tr>
<td>Spending too much money</td>
<td>0.0</td>
</tr>
<tr>
<td>Driving problems</td>
<td>0.0</td>
</tr>
<tr>
<td>Poor appetite</td>
<td>0.0</td>
</tr>
<tr>
<td>Low libido</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Highest-ranking problem (worst problem = 3, next worst = 2, third worst = 1, not mentioned as a problem = 0).

IADL, instrumental activity of daily living; OCD, obsessive-compulsive disorder; TBI, traumatic brain injury.
outcomes of greatest importance to the patient. Perhaps because the target outcome questions demonstrated our interest in what was most meaningful to veterans and their family members, they were well-received by research participants, who welcomed the opportunity to reflect on these questions and share their experience with TBI.

Findings also revealed different patterns in ranking of problems by veterans versus family members. Veterans ranked cognitive and physical problems significantly higher than did family members; by contrast, family members ranked emotional and interpersonal problems significantly higher than did veterans. Thus, veterans with TBI and family members found different types of TBI-related problems most troubling. This replicates research conducted with standardized measures of functional competence.  

Study Limitations
Caution should be used in generalizing these findings to other patient populations with TBI. The study sample comprised veterans with TBI who were patients at a VA medical center. Many veterans with TBI do not use VA medical centers for their care, and it is unclear how such patients differ from VA medical center patients. In addition, veterans in the sample were willing to participate in a study to evaluate an innovative program and had at least one relative also willing to participate. From that standpoint as well, the sample may not have been completely representative of patients with TBI. Finally, two-thirds of the study sample had a mild TBI. Findings for more severely injured patients with TBI may differ. An important direction for future research would be to use a target outcome approach in different kinds of TBI populations.

Implications for Clinical Practice
Although target outcomes were designed to yield patient-centered outcomes for research purposes (especially clinical trials), they have applications for clinical practice as well, providing a practical clinical tool for capturing the experience of living with TBI. In contrast to lengthy functional rating scales, target outcome questions represent a brief, less burdensome tool and may yield a more nuanced picture of the TBI’s impact on patients and families, one that allows for identifying unusual or idiosyncratic sequelae. They can help guide the focus of treatment to address the problems of most concern to patients and their families. During treatment, progress can be gauged in reference to the targeted outcome identified at the beginning. A focus on problems as described in patients’ and families’ own terms also may increase their engagement in the treatment process and treatment adherence. Further, targeted outcomes may shift over time during treatment, and therapists can easily update targeted outcomes that guide the dynamic treatment process.

In addition, questioning of both patients and their family members provides an opportunity to compare perceptions of the most troubling aspects of TBI. This information should facilitate communication between veteran and family member, providing each with insights into how the others view TBI-related problems and what troubles them the most. This process may enhance the openness of future communications, which has benefits for both veterans and family members.

CONCLUSIONS
Veterans with traumatic brain injury may not recognize the concerns that are most upsetting for family members; similarly, family members may not realize the problems most upsetting to veterans. Promoting dialogue around the target outcomes for both parties may enhance the capacity for empathy in both veteran and family member. Because families are the most important supports for these injured veterans, a deeper understanding of their relative’s TBI experience is important to their ability to care for and support the veteran.

Patient-Friendly Recap
• Traumatic brain injury (TBI) is common among armed service veterans and can result in cognitive, physical, emotional and interpersonal problems.
• The authors found that because such effects can be unpredictable and idiosyncratic, veterans and their respective family caregivers often disagree on the extent of the problems and which are most troublesome.
• Identifying any differences of opinion may enhance communication between patient and family and help guide a clinical course in treating TBI.
Acknowledgments
The research team gratefully acknowledges the veterans with traumatic brain injury and their family members who gave of themselves and their time to share their stories and take part in this study.

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Conflicts of Interest
None.

References
23. Winter L, Moriarty HJ, Piersol CV, et al. Efficacy and acceptability of a home-based, family-inclusive intervention for veterans with TBI: a randomized controlled trial. (Submitted manuscript under review.)
To determine traumatic brain injury (TBI) severity, a study co-investigator with expertise in rehabilitation medicine reviewed the subject’s electronic medical record and assigned a severity level using the VA/DoD Clinical Practice Guideline for Management of Concussion/Mild Traumatic Brain Injury. According to these guidelines, TBI injury severity is stratified across three levels (mild, moderate, severe) using five variables (reported findings on structural imaging based on radiographic reports, reported or documented length of time of loss of consciousness, reported or documented length of time of alteration of consciousness, reported or documented length of time of posttraumatic amnesia, and Glasgow Coma Scale [GCS] score at the time of the injury or injuries).

For our study population, GCS scores were unavailable. Data for the other four variables were consistently available in subjects’ medical records. When three or four of the variables were reported or documented as falling within the specified severity level (mild/moderate/severe), this level was assigned; if one or two variables fell across two or three specified severity levels (mild to moderate, moderate to severe), then the level was assigned as “transitional” in severity. Thus, the sample population is described across five levels of severity: mild, mild-moderate, moderate, moderate-severe, and severe. Although this approach is not usually taken during clinical TBI severity assignment when applying these guidelines, it provided a more refined description of severity stratification in our study population.