Behavioral and Cognitive Performance Baselines for Tailored, Integrated TBI Rehabilitation

Abstract ID: I805

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Abstract

Over 1.7 million traumatic brain injuries (TBI) occur annually in the US, as well as over 20% of deployed military service members. Although normative TBI data are available, each TBI experience is unique. Rehabilitation efforts aim to return the patient back to his or her previous cognitive baseline, but pre-trauma cognitive data rarely exists. Cognitive performance baselines should include both task outcome and cognitive effort or frustration. These subjective mental workload measures are commonly evaluated using tools such as NASA-TLX and SWAT, but have not yet been applied in the medical rehabilitation community. This research examines the desired content of pre-trauma cognitive data; storage and access of such data in electronic personal health and medical records; and the use of mental workload evaluations in the TBI rehabilitation process. The research incorporates both first-hand experience with TBI rehabilitation and examinations of rehabilitation therapy practice. The complexity and variety of critical pre-trauma and post-trauma data, including video and performance process / annotation, can ultimately provide a tailored, integrated TBI rehabilitation process.

Keywords
Human factors; TBI rehabilitation; cognitive baselines; subjective mental workload

1. Introduction

Traumatic brain injury (TBI) is a grave and substantial public health problem. According to the Center for Disease Control and Prevention (CDC), 1.7 million people in the United States experience a non-fatal TBI every year [1]. A TBI is caused by a blow, jolt, or penetrating wound to the head that disrupts normal brain function. The leading cause of TBIs is falls (35.2%) [1]. Figure 1 displays the distributed causes of TBI.

TBIs vary in acuteness from mild to moderate to severe. Refer to Table 1 to view the Department of Defense TBI Classification System [2]. Mild TBIs (mTBI), also called concussions, are the most common TBIs, constituting approximately 75% of total civilian TBIs [3]. mTBI is also one of the most common injuries sustained by military service members during Operation Enduring Freedom and Operation Iraqi Freedom [4]. Data suggest that at least 20% of the military service members may have suffered a mTBI during deployment [2]. However, this percentage is likely higher because many military service members do not seek medical care, thus the injuries go unreported [5]. Over the past few decades, there has been an increase in TBI survivors, both civilians and military service members, due to improved motor vehicle safety features, such as air bags and seatbelts, and improved body armor and helmets in the military theater [4].
Across all levels of severity, TBIs can produce long-term cognitive symptoms, such as headaches, dizziness, slowed thinking, confusion, memory loss, inattention, and delayed reaction time [2, 3, 6]. These impairments can have detrimental effects on a victim’s ability to navigate daily life. Furthermore, even subtle impairments, such as inattention, can negate a soldier’s ability to perform in the military theater, and thereby compromise the mission and endanger the lives of others.

An estimated 5.3 million Americans live with a permanent TBI-related disability today [7]. The direct medical costs and indirect costs of TBIs in the US is estimated to be $60 billion [7]. After surveying the severe impact TBIs have on the individual and society, the need for cognitive rehabilitation is apparent. Cognitive rehabilitation is "a systematic, functionally oriented service of therapeutic activities that is based on assessment and understanding of the patient's brain-behavioral deficits," as defined by the American Congress of Rehabilitation Medicine (ACRM) [6]. Cognitive rehabilitation is well accepted as a standard element of comprehensive rehabilitation for moderate and severe TBIs [8, 9]. Even though a meta-analysis demonstrated that the majority of adults have positive outcomes after a mTBI [10], cognitive rehabilitation is still applicable to mediate persistent symptoms caused by a mTBI [9, 11].

The ACRM Cognitive Rehabilitation Manual (CRM) states the primary goal of cognitive rehabilitation is to mitigate trauma-induced cognitive impairments so as “to maximize safety, daily functioning, independence, and quality of life.” [9] Patients expect and/or wish to return to their personal pre-trauma state. Rehabilitation efforts must focus on returning the patient back to his or her pre-trauma cognitive baseline (if possible), not necessarily the population norm.

### 2. Gaps in TBI rehabilitation

No two TBIs are the same in cause and presentation [12]. Moreover, evaluation of the neurobehavioral and psychosocial factors that influence the treatment process and patient outcomes has determined that patient variables are more important than injury-specific factors [9]. Patient variables include the patient’s values and priorities; history of managing stressful circumstances; level of self-worth and self-efficacy; and the emotional reaction to impairments and confronting the effects of the impairments. Intuitively, cognitive rehabilitation must be tailored to identify and address each patient’s specific needs.

#### 2.1 Lack of pre-trauma behavioral and cognitive performance baselines

A key difficulty in TBI rehabilitation is evaluating the patient’s performance with no pre-trauma cognitive baseline information available. Cognitive baseline testing is highly valuable because it increases the ability of the therapist, and other relevant caregivers, to detect post-trauma neurocognitive impairments [13]. Beyond detection, the baselines help determine the level of decrement (LOD; described below) between pre- and post-performance. Thus, this information will allow effective tailoring of the rehabilitation plan to accurately target the impairments and attempt to improve them to pre-trauma performance, if possible.

##### 2.1.1 Level of decrement

For the purpose of this research, the level of decrement (LOD) is defined as the loss of cognitive or behavioral performance in a patient as a result of a TBI. There can be many different types of decrements such as decrements in attention, memory, executive functioning, reading comprehension, and reading speed. Most decrements are interrelated, so it is useful to consider the LOD for each decrement rather than merely looking at a singular, composite score.

For clarity, consider the Intelligent Quotients (IQs) of two hypothetical patients (Figure 2): Patient A and Patient B. As defined by the Wechsler Adult Intelligence Test, IQs have a normal distribution with the median IQ as 100 (σ = 15) [14]. Post-trauma, Patient A has an IQ of 89, and categorized as “low average” [14]. The LOD for Patient A’s

<table>
<thead>
<tr>
<th>Classification</th>
<th>Duration of unconsciousness</th>
<th>Posttraumatic amnesia</th>
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<tbody>
<tr>
<td>Mild</td>
<td>&lt;30 min</td>
<td>&lt;24 hr</td>
</tr>
<tr>
<td>Moderate</td>
<td>30 min – 24 hr</td>
<td>1-7 days</td>
</tr>
<tr>
<td>Severe</td>
<td>&gt;24 hr</td>
<td>&gt;7 days</td>
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Table 1: DoD TBI Classification System [2]
IQ, with respect to the median IQ, is only 11 points. However, with respect to Patient A’s pre-trauma IQ, 131, is categorized as “superior” and the LOD is a devastating 42 points. Without the pre-trauma data, it appears Patient A’s rehabilitation needs are minimal when they are, in fact, quite significant. In contrast, Patient B’s post-trauma IQ, 78, is “borderline [intellectual disability].” The LOD with respect to the median is 22 points, suggesting intensive rehabilitation needs; but with respect to Patient B’s pre-trauma IQ, 88 and “low average,” the LOD is only 10 points. Recovery efforts to “return” Patient B to “normal” (or median) would be ineffective and wasteful.

![Figure 2: Example of the Level of Decrement for Patients A, B](image)

### 2.1.2 Patient impairment of awareness

Cognitive rehabilitation treatment typically begins assessments to identify and determine the characteristics of impairments of awareness [9]. Unawareness of personal impairments has substantial negative impacts on treatment outcomes, because patients have less motivation to engage fully in the rehabilitation process [9]. There are three primary causes of awareness impairments, namely: 1) neurocognitive factors; 2) psychological factors; and 3) social and environmental factors [15].

Pre-trauma cognitive baselines are useful in starting a rehabilitation treatment plan and goal. They can also assist in highlighting cognitive impairments such that the patient becomes more aware of his or her impairments. Although several cognitive rehabilitation strategies, such as executive functioning rehabilitation techniques, can be used to raise awareness of cognitive limitations for the patient [9], clear pre-trauma and post-trauma data concretely and objectively illustrate the existence and nature of the impairments. As with any impairment awareness intervention, it may be necessary to be cautious in presenting data starkly demonstrating impairments to a patient, particularly if the root cause of his or her unawareness is psychological factors (such as denial) [16].

### 2.1.3 Determining behavioral and cognitive baselines

Cognitive and behavioral baselines must be comprehensive, particularly encompassing both performance metrics and workload metrics. Performance metrics, such as error rates on an attention test, provides only a vague understanding of the patient’s current recovery state. For example, say a patient may have 40% correct answers for a test one day, and retest at the next therapy session only to again have 40% correct answers. With this data, there appears to be no cognitive progress. However, perhaps the patient felt “frustrated” and “mentally fatigued” after attempting the test the first session, but then felt only “frustrated” on the second session attempt. This indicates a worthy cognitive improvement because the patient was not cognitively fatigued by the test and has sufficient energy to try therapeutic exercises. Of course, the relevant question is: how do are cognitive and behavioral baselines determined?
A neuropsychological exam is helpful in determining a robust and comprehensive view of the patient’s current cognitive status and neurobehavioral and emotional state. Pre-trauma neuropsychological examination could be useful in determining the premorbid cognitive and behavioral baselines, but there will be challenges in determining the appropriate tests to comprise the exam.

During the rehabilitation phase, each neuropsychological exam is tailored for each patient. For example, a patient categorized as “high-performing” will be administered more challenging tasks, such as memory tests with longer content, such as a list of 16 items to listen and recite back, and then asked to recite back again after performing an unrelated memory task. However, consider if a (pre-trauma) high-performing “patient” takes a tailored exam, executing a variety of challenging tasks. Ideally, post-trauma this patient would take the same exam so as to have direct comparative results, but if the LOD is severe, the patient may not even be capable enough to perform the tasks he or she once performed pre-trauma. This context seems to indicate that pre-trauma exams be comprised of low intensity tasks, but this also lends to difficulties in rehabilitation tracking because if the post-trauma patient can perform at “low average,” there is no data to demonstrate the remaining decrement to return to “high-performing.” To achieve tailored TBI rehabilitation, the pre-trauma exam must be carefully tailored to the patient such that it is, in whole or in part, applicable to the post-trauma rehabilitation phase.

Another challenge is the length of the exam (approximately 8hrs), so it may be difficult engaging pre-trauma “patients” such that they are motivated to perform tasks, particularly “borderline [intellectual disability]” and “low average” ones. Lack of motivation could lead to invalid (and, thus, useless) results. Additionally, the exam is expensive due to the time duration and the personnel required, specifically a TBI-trained nurse to administer the exam and a neuropsychologist to review and generate a report about the exam. Implementing a pre-trauma neuropsychology exam would require careful considerations on the content and cost of the exam.

3. Considerations for improving mTBI rehabilitation assessments

3.1 Assessing subjective mental workload

Cognitive decrements impact both the performance outcome of the patient and the mental strain on the patient to perform. Thus, performance baselines, both pre-trauma and during cognitive rehabilitation, should include the outcome and the amount of cognitive effort for performing. For example, the patient may gain back a high level of reading comprehension, but reading speed may be slower than pre-trauma.

No care provider or family member can easily determine the subjective or true mental effort the TBI patient requires to execute each task. What is more readily measurable, however, is the patient’s perceived mental workload. The ACRM CRM consistently recommends therapists activate self-reflection in patients (unless sufficient self-awareness does not yet exist) by “solicit[ing] the patient’s opinion about their performance [of a task] and provid[ing] constructive feedback” (pg.65) [9]. However, this data is open-ended and not quantified. Presently, we can project that subjective mental workload measurements could be used in conjunction with the open-ended probing questions regarding patient self-reflection with respect to a specific task or metacognition strategy. Metacognition is “thinking about thinking,” and is a two-part entity: 1) metacognitive knowledge, referring to the patient’s current awareness of his or her thinking activity as well as his or her cognitive abilities; and 2) metacognitive control, referring to the patient’s self-monitoring of thinking and adjusting to environmental and task-demand changes [17].

Several subjective workload measures already exist. These tools were developed in human factors in industrial settings to determine the difference between the cognitive demands of a specific task or task set and the worker’s cognitive resources [18]. The goal of workload measurement is to develop tasks whose demands can be regulated such that the operator is neither under- nor over-loaded, thereby promoting health, safety, and productivity [19]. However, none have been applied in the medical rehabilitation community. Table 2 summarizes the factors the techniques measure [19]. Each technique requires operators to rate each factor on a specific scale, data which are then used to calculate a weighted composite score [19].
Subjective mental workload measures would greatly assist in tracking the patient’s rehabilitation progress. The CRM states that “[a] theory-driven approach ensures a meaningful rationale for the treatment approach being used” (pg. 75); thus performance tracking allows for data-based treatment and justification for treatment approaches [9]. A patient may not be improving in terms of outcomes, such as scoring the same on a memory test, but may report less frustration, indicating that progress does exist because the mental workload is decreasing, which will ultimately improve patient performance in the long run.

### 3.1 Appropriate applications of subjective mental workload measurements

Initial analysis has indicated that subjective mental workload measures could be integrated into TBI rehabilitation therapy. However, because TBI patients are typically unaware of their impairments immediately post-trauma, many cognitive therapy approaches are not usable during the acute-rehabilitation stage.

<table>
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<th>Pre-trauma</th>
<th>Trauma</th>
<th>Acute rehabilitation</th>
<th>Cognitive rehabilitation</th>
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Subjective mental workload measures require self-reflection and self-awareness, and should not be attempted until sufficient executive functioning is present. Figure 3 outlines the trauma stages: Pre-trauma, Trauma, Acute rehabilitation, and Cognitive Rehabilitation. Dark shading indicates a lack of self-awareness (i.e. the patient is “in the dark”).

### 3.2 Executive Functioning

Executive functioning is the “integrative cognitive processes that determine goal-directed and purposeful behavior” [9]. It has an immense impact on performing daily life functions such as planning and organizing behavior, problem-solving, and monitoring and adjusting behavior to fit a particular task or context [9].

Subjective mental workload measurement tools, such as SWAT and NASA-TLX, could be applied to TBI rehabilitation because they are similar to other executive functioning rehabilitation strategies. However, as with the executive functioning rehabilitation strategies, subjective mental workload techniques should only be applied in the post-acute trauma phase. This is because impairment awareness must be present so these techniques can be used effectively.

### 3.3 Attention

Attention is a composition of interrelated sub-processes. The clinical model of attention is divided into five hierarchically organized components: focused attention, sustained attention, selective attention, alternating attention, and divided attention. Even subtle impairments of attention can substantially decrease the patient’s ability to execute daily life activities [9].

Similar to executive functioning, attention rehabilitation treatments should be done during post-acute rehabilitation; no current research supports the use of attention treatments during the acute rehabilitation phase [9]. Attention interventions should be grounded in theoretical models. Hence, subjective mental workload techniques can...
effectively be applied to rehabilitation for attention impairments, assuming the patient has gain sufficient awareness and attention capabilities to evaluate a task.

3.4 Memory
Memory sub-processes include: 1) attention; 2) encoding; 3) storage (or retention); and 4) retrieval. Attention is a prerequisite of memory; thus, some patients may display and assert that they suffer from memory impairments, when, in fact, there difficulties to remember is a function of attention impairments [9]. Regardless, memory rehabilitation strategies will likely be needed.

The more severe the memory impairments are, the more there is a need for the patient to use more external cues rather than internal cues to manage the memory impairments and perform at a satisfactory level [9]. Common external cues include smart cell phones (to set alarms and reminders) and memory notebooks or other planning system. External cues are chosen based on: 1) the specific task; 2) the patient’s goals, abilities, disabilities, and preferences; 3) the physical features (or limitations) of tool; and 4) the environment in which the tool will be used. The specificity of external memory cues particularly lend themselves to being analyzed using subjective mental workload measures, and thus better determine the cognitive strain of the patient and to evaluate whether the particular cue is effective in the specific application of it to assist the patient.

3.5 Social communication
Social communication is very complex, and it would be difficult (if not impossible) to systematically measure the mental workload for a patient experiencing social communication impairments. The tests and exercises for social communication rehabilitation may only be useful during rehabilitation because attempts to determine pre-trauma cognitive and behavioral performance could yield invalid results. It may be difficult to engage some people as they perform “obvious” exercises, such as identifying the emotion associated with the facial expression of a person in a photograph. However, persons on the autistic spectrum or those with particular forms of face blindness, may have difficulty performing some of these social communication tests. Furthermore, communication norms in the military differ from those in the civilian world; thus, pre-trauma military personnel might appear to be lacking certain social communication skills because the rehabilitation exercises are not tailored to the military culture.

The root cause of social communication impairments is often due to other cognitive impairments (memory, attention, etc.), so it may be redundant to try to assess certain social communication abilities pre-trauma. Moreover, determining the nuances of social communication for special demographics is an area in need of research. For the purpose of this research, impairments of social communication will be excluded in pre-trauma assessments and fo the Individual Cognitive Health Report (ICHR; see below).

3.6 Hemispatial neglect
Hemispatial neglect is a reduction in attending and responding to objects on the left side, though the patient may still retain full visual fields. This phenomenon is caused by right brain damage. Although it could seem like testing hemispatial neglect pre-trauma (because no neglect exists) may be impractical or not useful, many hemispatial neglect rehabilitation procedures could still derive valuable information with respect to the pre-trauma behavioral and cognitive baselines. The Verbal Scanning Cancellation Test, which aids in assessing hemispatial neglect but is also applicable for attention assessment, would be worthwhile pre-trauma because it can be used for direct comparison of the patient’s post-trauma performance with respect to error rates (omissions and commissions) and the time to complete. Subjective mental workload measurements would help to expand the baseline data so the therapist has a comprehensive understanding of the patient’s pre-state.

3.7 Caregiver data storage and sharing
“Record-keeping of performance allows for data-based treatment. Careful records of performance during training allow the clinician to make informal decisions about when to start, stop, or modify a therapy program based on patient performance” (pg. 75) [9]. The cognitive rehabilitation team is comprised of a variety of clinicians, including physicians, nurses, neuropsychologists, speech pathologists, therapists (physical, occupational), and psychologists. All team members must communicate efficiently and effectively to provide integrative TBI care.

The author’s personal experience at a rehabilitation hospital found that the therapists, though diligent in their record-keeping, disliked the information presentation format of the electronic records. One therapist commented that health insurance personnel also found the rehabilitation notes to be difficult to read and navigate. The author herself found
it challenging to understand what was done at each therapy session based on the medical records presented. There is a need for a robust and flexible database with which all relevant professional caregivers can access the patient's records (medical, physical, therapeutic).

TBI rehabilitation is unique in that a wide variety of neurobehavioral and psychosocial factors influence treatment processes and outcomes. A single score to describe the patient’s cognitive state would provide no knowledge of how to guide treatment; thus, comprehensive data is necessary to deliver the best outcomes. The database suggested above must be designed to store diverse content and different media. For example, consider the evaluation of an alternating attention task. The patient will listen to a series of numbers, 1 or 2, and press a clicker once if the number is 1 and press twice if the number is 2. When the speaker says “switch,” the clicking rule changes to two clicks for the number 1 and one click for the number 2; several “switch” commands will occur over the number series. This task permits many quantitative and qualitative attention measurements.

Quantitative measures include accuracy, such as errors (omissions and commissions); this type of data is easily stowed in common databases. Some qualitative measures can be stored with simple text or coded; examples include the complexity of the task (simple, moderate, complex), the level of cueing or assistance needed (none, mild, moderate, maximum). Some qualitative measures may be more difficult to store, such as information about patterns of errors, patient factors and reactions (fatigue, depression, anxiety, pain, etc.), and environmental factors (noise, temperature, interruptions, etc.). Videos and annotations about the patient’s process of performance would also yield valuable knowledge about the patient’s cognitive state. The complexity and variety of critical pre-trauma and post-trauma data can ultimately deliver a tailored, integrated TBI rehabilitation process.

3.7.1 Individual Cognitive Health Report
TBI patients and their families often crave to know when the patient will be “better.” Moreover, patients are not always aware of their cognitive progress, which is often incremental, and they may become depressed thinking they will be “stuck like this forever.” Tracking and reporting the cognitive state and rehabilitation trajectory would greatly benefit the patient and his or her family members by reducing anxiety and increasing morale. From the results stored in the databases, an Individual Cognitive Health Report (ICHR) could be generated. The ICHR would be an easy-to-use report for patients to reference, both pre-trauma and post-trauma. Further research is needed to determine the appropriate content and information presentation design for the ICHR.

One of the many useful aspects of the ICHR is that it includes an estimation of intelligence. Many people are wary about using intelligence tests, particularly in the military, primarily due to concerns of discrimination based on an IQ score. Nonetheless, the ICHR provides intelligence estimates, which are accompanied by many other cognitive measurements to provide a more rounded view of the “patient’s” cognitive abilities. Because determining this information comes from a medical environment rather than a “company-based” exam, the results may seem more approachable, more reputable, more trustworthy, and private (thus protected from perceived risks of the “company” using the results for non-medical purposes).

4. Conclusions and future work
Traumatic brain injury (TBI) is a serious health problem in the United States. Each TBI is different and each patient has different outcomes as a result of the TBI. Pre-trauma cognitive and behavioral baselines provide invaluable data about a TBI patient’s cognitive state, which can be used for comparison during post-trauma cognitive rehabilitation. These comparisons allow the clinician to determine the Level of Decrement (LOD) with respect to the patient’s pre-trauma state rather than with respect to the population average. Pre-trauma baselines not only assist in treatment decisions, but can also be used to assist patients who have impairments of awareness. Without awareness, it is not possible to adequately motivate a patient to engage fully in rehabilitation treatment plans.

In determining behavioral and cognitive performance baselines, there is a need to find or develop cost-effective methods and processes to obtain cognitive data (pre- and post-trauma). To achieve tailored TBI rehabilitation, the pre-trauma exam must be carefully tailored to the patient such that it is applicable to the post-trauma rehabilitation phase. The pre- and post-trauma tests should contain the same content so direct comparisons can be made.

Subjective mental workload tools could be applied in adjunction with current cognitive rehabilitation techniques. Each tool (NASA-TLX, SWAT, WP) should be evaluated to determine which will most benefit TBI rehabilitation. Furthermore, additional research is needed to assess how to integrate them in a clinical center. Subjective mental
workload tools should only be used after acute rehabilitation and until the patient has sufficient self-awareness and executive functioning to perform self-reflection.

Good collaboration will give a more integrative therapy plan. To develop a robust and flexible database to store medical records, particularly cognitive rehabilitation tracking content, current information-sharing practices amongst a rehabilitation team should be mapped such that we can discover how caregivers share information. Mapping lays the foundation to evaluate the necessary requirements to build such a database. Once the database is built, including content storage rules and human-computer interfaces, we can consider how to extract and present cognitive health information in an Individual Cognitive Health Report (ICHR). The ICHR provides relevant, personalized cognitive health information such that the patient’s cognitive state is defined and that the cognitive rehabilitation trajectory can be tracked.

Acknowledgements
The first author would like to recognize her out-patient cognitive rehabilitation team at the Rehabilitation Hospital of Indiana (RHI), specifically Beth Helton, speech pathologist; Dr. Lisa Lombard, MD; Dr. Brad Hufford, PhD; and Dr. Lance Trexler, PhD, for their assistance in directing her to relevant resources and for their dedicated support in healing her. She also thanks the Purdue University Graduate School for granting her the Purdue Doctoral Fellowship, and the School of Industrial Engineering for managing her academic standing during trauma and acute rehabilitation. Without this support, this research would not be possible.

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