



REPORT TO CONGRESS

# Traumatic Brain Injury In the United States: Epidemiology and Rehabilitation

Submitted by the Centers for Disease Control and Prevention  
National Center for Injury Prevention and Control  
Division of Unintentional Injury Prevention



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## TBI Health Effects

A TBI can result in health effects that vary in intensity, length, and clinical manifestation. These health effects can persist and contribute to potential impairment, functional limitation, disability, and reduced quality of life (Riggio and Wong, 2009; Walker and Pickett, 2007). Disturbed cognition is the hallmark symptom of TBI but the injury also can affect behavior, emotion, and motor function. Cognitive disturbances can lead to difficulties with memory, attention, learning, and coordination. Other signs and symptoms include headaches, fatigue, and sleep disturbances. In addition, secondary neurologic disorders such as mood disorders and post-traumatic epilepsy can occur following TBI and disrupt health-related quality of life (Rosenthal, Christensen, and Ross, 1998; Hart, Brenner, Clark, Bogner, Novack, Chervoneva, Nkase-Richardson, and Arango-Lasprilla, 2011; Lowenstein, 2009; Agrawal, Timothy, Pandit, and Manju, 2006). The scientific literature also suggests that TBI increases the risk for neurodegenerative disorders, such as dementia. However, a majority of persons, particularly those with mild TBI, will generally experience one or more of these health effects for a short time following the injury. Repeated TBIs, though, can have prolonged and long-term effects. Finally, TBI can negatively affect families. Adverse family effects can include caregiver distress, depression, and deterioration of family functioning after a TBI (Aitken et al., 2009; Wade, Carey, and Wolfe, 2006b).

## Effectiveness of TBI Outcome Measures

TBI outcome measures can be broadly defined as instruments or scales that assess physical and cognitive ability, as well as psychological functioning, after the injury. There can be a wide range of short- and long-term outcomes resulting from a TBI. Accurately measuring these outcomes is critical given the important purposes for which measurement results are used. First, outcome measurement helps assess the status of recovery and effectiveness of rehabilitation. Second, measurement results can be used to monitor the progress of treatment in the clinical setting and demonstrate treatment progress to a third-party payer. Finally, these outcomes undergird research on the effectiveness of TBI rehabilitation and better inform future clinical interventions and recovery.

The TBI Outcomes Workgroup of the Common Data Elements (CDE) Project identified the critical outcome domains for TBI outcomes research (Wilde et al., 2010) as follows:

- Global Outcome
- Recovery of Consciousness
- Neuropsychological Impairment
- Psychological Status
- TBI-related Symptoms
- Behavioral Function
- Cognitive Activity Limitations
- Physical Function
- Social Role Participation
- Health-Related Quality Of Life
- Health-Economic Measures
- Patient-Reported Outcomes

The TBI CDE Outcomes Workgroup also identified a set of recommended measures within each outcome domain. These recommended measures were those with the strongest level of research support. However, these measures require several hours to implement. One of the current goals of the National Research Action Plan (NRAP), a federal interagency group that is charged with coordinating TBI research, is the development of a shorter but comprehensive assessment tool that is sensitive across the range of TBI severities. In addition, the authors of the NRAP have acknowledged that the limited effectiveness demonstrated by previously conducted intervention studies, including those in rehabilitation, have been caused in part by the limited number of validated assessment tools that are sensitive enough to detect treatment effects. The TBI CDE Outcomes Workgroup also identified several measures within each domain that are promising and that have the potential to surpass the currently recommended measures. The TBI CDE Outcomes Workgroup indicated that these measures require additional study to warrant inclusion as a recommended tool to assess a particular element within an outcome domain.

A separate pediatric workgroup identified additional CDEs and associated measures for children, specifically related

to academics, adaptive and daily living skills, family and environment, language and communication, and social cognition (McCauley et al., 2012).

The taxonomy developed by the TBI CDE Outcomes Workgroup has the potential to bring greater consistency to TBI-related outcomes that will improve the quality and comparability of TBI research.

Finally, a multicenter study, Transforming Traumatic Brain Injury Research and Clinical Care (TRACK-TBI), evaluated the feasibility of implementing a wide range of the TBI CDEs in a single study of adults with TBI. This study found that assessing a large number of TBI CDEs was feasible. However, several gaps in the study were identified, including the need for validating additional outcome measures for TBI patients living with higher levels of disability and the need for validating additional outcome measures among non-English speaking patients.

## Factors Influencing Outcomes

Intervening factors that have been shown to influence outcomes must be considered when interpreting research examining the effectiveness of rehabilitation. Aside from the type and severity of a TBI, and the medical care received, recovery from TBI is influenced by factors including individual patient characteristics, social-environmental factors, and access to rehabilitation services.

Individual characteristics, such as age and pre-injury functioning, can influence outcomes after TBI. The degree to which they influence outcomes depends upon the severity of injury. Social-environmental factors (e.g., socioeconomic status, social support, caregiver and family functioning) also can influence outcomes after TBI. Finally, access to rehabilitation services can be negatively impacted by a lack of specialty providers, particularly in rural areas, as well as a lack of financial resources available to a person with TBI. The availability and level of insurance coverage are especially important.

## Effectiveness of TBI Rehabilitation

Following hospitalization for a TBI, persons can receive rehabilitation care and services in various settings. Post-acute rehabilitation is provided following an inpatient hospital stay and is typically indicated for persons whose medical condition requires continued skilled nursing

care. Some settings in which this level of rehabilitation is available includes inpatient rehabilitation facilities, long-term care hospitals, and skilled nursing facilities. Persons who no longer require skilled nursing care are usually discharged home and may receive rehabilitation care provided by outpatient and community service centers. However, the type of rehabilitation care or setting selected is also based on a person's level of functional recovery, independence, geographic availability, and financial resources—including insurance coverage.

For persons living with TBI-related health effects, rehabilitation goals are structured to improve their independence in activities of daily living, social functioning, quality of life, and ability to participate in the community. They typically focus on the recovery of motor function, cognitive function, self-care skills, and community participation. A person's pre-injury functioning and personal goals are fundamental in determining the best rehabilitation treatment plan, as well as the eventual outcomes. No single TBI rehabilitation program will work for all patients; rather, the goals and methods of rehabilitation must be individualized to each person.

TBI rehabilitation consists of therapies broadly categorized as cognitive and physical. Cognitive rehabilitation (CR) consists of a group of therapies used to manage deficits in thought processes and behavior (e.g., comprehension, perception, and learning). Physical rehabilitation focuses on enhancing different forms of mobility by improving physical factors such as strength and endurance, as well as providing assistive devices that facilitate independence.



## Cognitive Rehabilitation

The Cognitive Rehabilitation (CR) Task Force of the American Congress of Rehabilitation Medicine (ACRM) Brain Injury Interdisciplinary Special Interest Group evaluated 370 studies and found that CR is effective during the post-acute period—even 1 year or more after injury (Cicerone et al, 2000, 2005, 2011). Further analysis of the scientific literature suggests that CR is effective in patients with moderate and severe TBI (Rohling et al., 2009). However, an Institute of Medicine (IOM) committee concluded that the evidence was insufficient to provide practice guidelines, particularly with respect to selecting the most effective treatments for a specific person (IOM, 2011). The insufficiency of the evidence was largely attributed to limitations in research designs for rehabilitation evaluation studies. And yet, empirical support for CR is growing with the strongest level of evidence for the following interventions (Cicerone et al., 2011):

- Direct attention training accompanied by metacognitive training to promote development of compensatory strategies and generalization;
- Interventions to address functional communication deficits and memory strategies for mild memory impairments;
- Meta-cognitive strategies for executive function deficits; and
- Comprehensive holistic neuropsychological rehabilitation.

Preliminary evidence supports the effectiveness of group-based rehabilitation treatment of pragmatic communication disorders. However, research that demonstrates the effectiveness of cognitively based treatments for listening, speaking, reading, and writing, in social, educational, occupational, and community settings is lacking (Turkstra et al., 2003).

## Physical Rehabilitation

Evidence supports the general effectiveness of physical rehabilitation (Bland, Zampieri-Gallagher, and Damiano, 2011; Betker, Desai, Nett, Kapadia, and Szturm, 2007; Irdesel, Aydiner, and Akgoz, 2007; Mossberg, Amonette, and Masel, 2010; Scherer and Schubert, 2009; Shaw et al., 2005). With respect to specific interventions, regularly scheduled passive range-of-motion exercises and body re-positioning are techniques that are commonly used with positive effects (Winkler, 2013). Equipment, such as standing frames or tilt tables, can be used to maintain bone structure, elongate shortened muscles, challenge endurance, and stimulate the minimally conscious person. Body-weight-supported (BWS) gait devices and knee-ankle-foot orthotics can be used with manual assistance to initiate standing postures. BWS devices can lead to improved cardiovascular function and assist with the beginning of walking training (Mossberg, Orlander, and Norcross, 2008; Wilson and Swaboda, 2002).

Gaming and virtual reality-based treatment methods are emerging as an adjunct to physical therapy standards of practice for treating persons with TBI (Betker et al., 2007; Scherer and Schubert, 2009). One study demonstrated the effectiveness of improved goal-oriented, task-specific training with the use of a gaming system to promote practice of short sitting balance control for persons with TBI. Another method used a game-based training tool that yielded an increase in practice volume and attention span, and furthermore, improvements in dynamic sitting balance control (Betker et al., 2007). Certain evidence indicates that virtual reality and other methods to improve vestibular function and balance result in improvements in both gait and gaze stability of persons with TBI sustained during blasts (Scherer and Schubert, 2009). However, approaches such as motor interventions, proprioceptive muscle training, and neurodevelopmental treatment have been used in clinical practice with limited research on their effect on functional outcomes.

## Recommendations

The following section lists recommendations to address gaps identified in each of the major sections in this report. The full report provides additional background and describes the critical gaps that are addressed by the following recommendations:

### Section I. Epidemiology and Consequences of TBI in the United States

- *Improve TBI incidence and prevalence estimates to include patients with TBI who are treated in non-hospital settings and those with TBI who are not receiving medical care.* Develop or identify sources of non-hospital TBI incidence data, such as data from physician offices and other sources of outpatient medical encounters, to improve estimates. Similarly, develop or identify data sources that capture information from persons who might have experienced a TBI but did not seek medical care for their injury.
- *Generate state-specific TBI estimates.* Collect and compile health care administrative data in all states to quantify and examine state-level variations in TBI burden. In addition, state-level TBI estimates can be used to inform decisions related to the allocation of preventive and rehabilitative services that are made at the state level.
- *Better understand injury mechanisms and their effect on sub-populations.* Examine trends in TBI incidence by injury mechanism and within population subgroups (e.g., children, older adults, and others) by using data systems such as Healthcare Cost Utilization Project (HCUP). This can help target prevention resources to populations at greatest risk for TBI.
- *Enhance monitoring of sports and recreation concussions.* Develop and implement a concussion surveillance system that captures the full range of sports- and recreation-related concussions. Current surveillance systems capture only emergency department visits or injuries experienced in organized high school sports, collegiate athletics, and some professional leagues.
- *Produce population-level estimates of TBI-related disability.* Add TBI-related disability to large, existing national health surveys, and analyze large-scale claims or administrative datasets to produce population-level estimates.