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ORIGINAL ARTICLE

Functional Outcomes in Traumatic Disorders of Consciousness: 5-Year Outcomes From the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems

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Abstract

Objective: To characterize the 5-year outcomes of patients with traumatic brain injury (TBI) not following commands when admitted to acute inpatient rehabilitation.

Design: Secondary analysis of prospectively collected data from the National Institute on Disability and Rehabilitation Research–funded Traumatic Brain Injury Model Systems (TBIMS).

Setting: Inpatient rehabilitation hospitals participating in the TBIMS program.

Participants: Patients (N = 108) with TBI not following commands at admission to acute inpatient rehabilitation were divided into 2 groups (early recovery: followed commands before discharge [n = 72]; late recovery: did not follow commands before discharge [n = 36]).

Interventions: Not applicable.

Main Outcome Measures: FIM items.

Results: For the early recovery group, depending on the FIM item, 8% to 21% of patients were functioning independently at discharge, increasing to 56% to 85% by 5 years postinjury. The proportion functioning independently increased from discharge to 1 year, 1 to 2 years, and 2 to 5 years. In the late recovery group, depending on the FIM item, 19% to 36% of patients were functioning independently by 5 years postinjury. The proportion of independent patients increased significantly from discharge to 1 year and from 1 to 2 years, but not from 2 to 5 years.

Conclusions: Substantial proportions of patients admitted to acute inpatient rehabilitation before following commands recover independent functioning over as long as 5 years, particularly if they begin to follow commands before hospital discharge.

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Survivors of severe traumatic brain injury (TBI) may experience prolonged disorders of consciousness (DOC), including the vegetative state (VS) and minimally conscious state (MCS).[1] Among this group, many are left with severe disability as measured by the Glasgow Outcome Scale (GOS).[1] However, few studies have followed up patients beyond 12 months postinjury, limiting the opportunity to investigate the incidence of late recovery of key functional milestones. In addition, the GOS "severe disability" category encompasses patients with a broad range of functional outcomes, including individuals who remain noncommunicative and unable to assist with basic self-care activities as well as those able to communicate reliably and independently perform basic activities of daily living. Not surprisingly, given the limited empirical data available about long-term outcome in these patients, health care providers often predict a less favorable functional outcome than eventually occurs.[2] Perhaps partly because of this negative impression, patients with DOC are viewed by many clinicians and payers as inappropriate for acute inpatient rehabilitation.[3,4]

Over the past decade, the body of literature regarding the natural history of DOC after an acquired brain injury has grown. The accumulating literature has begun to demonstrate a more favorable prognosis for certain subsets of those with DOC. Specifically, those with traumatic etiologies[1,5,6] and a diagnosis of MCS (as opposed to VS) at the time of rehabilitation admission[5-7] have demonstrated a better prognosis, in terms of both recovery of consciousness[5,7,8] and recovery of functional independence.[5,8-11]

Studies[5,7-11] with longer follow-up intervals demonstrate favorable functional outcomes in a substantial minority of cases, and clinically meaningful recovery continuing as long as 5 years postinjury in those who remain in VS or MCS during the first year.[8,10,12] Among those who demonstrate such late recovery, as many as 20% eventually achieve household independence, return to work or school, or both.[5,8] The probability of late functional recovery appears to be significantly higher after TBI and in those with diagnosed MCS versus those in VS or nontraumatic MCS.[6,10]

At 2 and 5 years postinjury, DeGuise et al[11] assessed functional outcome in 46 patients originally admitted to an acute care setting with severe TBI. The authors observed improvement in ratings on the FIM, GOS–Extended, and Neurobehavioral Rating Scale–Revised between years 2 and 5. Katz et al[5] monitored recovery for 1 to 4 years in a cohort of 36 individuals with TBI or non-TBI (primarily vascular and anoxic etiologies) who were admitted to inpatient rehabilitation with an ongoing disturbance in consciousness. At the time of the last available follow-up, 72% had emerged from MCS, 58% had cleared posttraumatic amnesia (PTA), 43% achieved household daytime independence or better, and 22% returned to work or school (17% at or near preinjury levels). Etiology (traumatic vs nontraumatic), diagnosis (MCS vs VS), duration of MCS, rehabilitation discharge FIM score, and age predicted late outcome. Estraneo et al[12] followed up 50 patients in prolonged VS (up to 2y) and reported that 20% recovered consciousness between 12 and 24 months. In addition, 12% of those with late recovery of consciousness subsequently emerged from MCS.

More recently, members of the Traumatic Brain Injury Model Systems (TBIMS) published a retrospective review[8] of long-term outcomes attained by 396 individuals who were unable to follow commands at the time of admission to inpatient rehabilitation. During the inpatient stay, 68% regained consciousness and 23% emerged from PTA. Those who did not recover consciousness by the time of rehabilitation discharge (n = 128) showed a high incidence of late recovery of consciousness at follow-up years 1, 2, and 5 (respectively 59%, 66%, and 74%). Significant improvements were achieved from the time of rehabilitation admission to rehabilitation discharge on the FIM. Among those with follow-up data, 19.6% were living without in-house supervision, and 18.7% were judged to be employable as measured by the Disability Rating Scale (DRS).[8] There were significant improvements in this total sample from rehabilitation discharge to 1 year, and from 1 to 2 years in all functional outcomes assessed. Improvement from 2 to 5 years was still significant for the FIM cognitive subscale, but motor subscale improvement was only marginally significant.[8] Although the subscale scores of the FIM are meaningful, a detailed description of ability to engage in activities of daily living can be more meaningful. Further, the expected recovery for individuals who regain consciousness during rehabilitation may differ for those who do not regain this ability. Despite using longer follow-up intervals, many of the above studies defined outcome in gross and often binary ways (eg, conscious/not conscious), so that it remains difficult to project more specific outcomes such as communication and ambulation.

The primary aim of the current study was to characterize with greater precision the long-term recovery patterns and functional outcomes of individuals enrolled in the TBIMS database[8] who failed to clearly demonstrate command-following before rehabilitation admission. To accomplish this, we stratified subjects drawn from the TBIMS national database into 2 subgroups—those who were not following commands at the time of rehabilitation admission but who began doing so during their rehabilitation stay, and those who failed to demonstrate command-following by the time of inpatient rehabilitation discharge—and compared their outcomes on the items of the FIM at 1, 2, and 5 years postinjury. Specifically, we examined the proportion of people in both of these subgroups who became independent on each FIM item.

List of abbreviations:

DOC	**disorders of consciousness**
DRS	**Disability Rating Scale**
GCS	**Glasgow Coma Score**
GOS	**Glasgow Outcome Scale**
MCS	**minimally conscious state**
PTA	**posttraumatic amnesia**
TBI	**traumatic brain injury**
TBIMS	**Traumatic Brain Injury Model Systems**
VS	**vegetative state**

Methods

Participants

Participants were enrolled prospectively in the TBIMS national database, a multicenter longitudinal study of TBI funded by the National Institute on Disability and Rehabilitation Research. Currently, there are 16 sites across the country enrolling subjects in the database, which has been in existence since 1988. All TBIMS enrollees are 16 years or older, received medical care in a TBIMS-affiliated acute care hospital within 72 hours of injury, and were transferred directly from acute care to an affiliated comprehensive inpatient rehabilitation program. See Gordon et al[13] for TBIMS inclusion and exclusion criteria. Informed consent was provided by a legally authorized representative.