Published in final edited form as:

J Head Trauma Rehabil. 2012 November ; 27(6): 391–403. doi:10.1097/HTR.0b013e3182238cdd.

Representativeness of the Traumatic Brain Injury Model Systems National Database

John D. Corrigan, PhD¹, Jeffrey P Cuthbert, MPH, MS², Gale G. Whiteneck, PhD², Marcel P. Dijkers, PhD³, Victor Coronado, MD, MPH⁴, Allen W. Heinemann, PhD⁵, Cynthia Harrison-Felix, PhD², and James E. Graham, PhD⁶

¹Department of Physical Medicine and Rehabilitation, Ohio State University, Columbus OH

²Research Department, Craig Hospital, Englewood CO

³Department of Rehabilitation Medicine, Mount Sinai School of Medicine, New York NY

⁴National Center for Injury Prevention and Control, Centers for Disease Control and Prevention, Atlanta GA

⁵Department of Physical Medicine and Rehabilitation, Feinberg School of Medicine, Northwestern University and the Rehabilitation Institute of Chicago, Chicago IL

⁶Division of Rehabilitation Sciences, University of Texas Medical Branch, Galveston TX

Abstract

Objective—To determine whether the Traumatic Brain Injury Model Systems National Database (TBIMS-NDB) is representative of individuals aged 16 years and older admitted for acute, inpatient rehabilitation in the United States with a primary diagnosis of traumatic brain injury (TBI).

Design—Secondary analysis of existing datasets.

Setting—Acute inpatient rehabilitation facilities.

Participants—Patients 16 years of age and older with a primary rehabilitation diagnosis of TBI.

Interventions—None.

Main Outcome Measure—demographic characteristics, functional status and hospital length of stay.

Results—From October 2001 through December 2007 patients included in the TBIMS-NDB were largely representative of all individuals 16 years and older admitted for rehabilitation in the U.S. with a primary diagnosis of TBI. The major difference in distribution was age—the TBIMS-NDB cohort did not include as many patients over age 65 as were admitted for rehabilitation with a primary diagnosis of TBI in the United States. Distributional differences for age-related characteristics were observed; however, groups of patients partitioned at age 65 differed minimally, especially the under 65 subset. Regardless of age, the proportion of patients with a rehabilitation stay of 1-9 days was larger nationwide. Nationwide admissions showed an age distribution similar to patients discharged alive from acute care with moderate, severe or penetrating TBI. The proportion of patients age 70 and older admitted for TBI rehabilitation in the

Please direct all correspondence and request for reprints to: John D. Corrigan, PhD, corrigan.1@osu.edu, telephone: (614) 293-3830, Department of Physical Medicine and Rehabilitation, Ohio State University, 480 Medical Center Drive, Columbus, OH 43210.

No commercial party having a direct financial interest in the results of the research supporting this article has or will confer a benefit upon the authors or upon any organization with which the authors are associated.

United States increased every year, a trend that was not evident in the general population, TBIMS-NDB or among TBI patients in acute care.

Conclusions—These results provide substantial empirical evidence that the TBIMS-NDB is representative of patients receiving inpatient rehabilitation for TBI in the U.S. Researchers utilizing the TBIMS-NDB may want to adjust statistically for the lower percentage of patients over age 65 or those with stays less than 10 days.

Keywords

craniocerebral trauma; traumatic brain injury; rehabilitation; methodology

Since 1987, the National Institute on Disability and Rehabilitation Research (NIDRR) in the US Department of Education has funded the Traumatic Brain Injury Model Systems (TBIMS) program. At the core of this program is a prospective, longitudinal, multicenter inception cohort used to study the course of recovery and outcomes following traumatic brain injury (TBI).¹ The TBIMS National Database (TBIMS-NDB) contains information on cases treated in TBIMS-funded centers since 1988. There are currently 16 centers distributed around the United States that successfully competed for research funding and four, previously fully-funded centers that continue to collect follow-up data on subjects they enrolled. For purposes of the TBIMS-NDB data collection, TBI is defined as damage to brain tissue caused by an external mechanical force as evidenced by medically documented loss of consciousness or post-traumatic amnesia (PTA), or by objective neurological findings on physical or mental status examination that can be reasonably attributed to TBI.² In addition, subjects included in the TBIMS-NDB must (1) meet at least one of the following criteria for moderate to severe TBI: (a) PTA > 24 hours; (b) trauma-related intracranial neuroimaging abnormalities; (c) loss of consciousness exceeding 30 minutes (unless due to sedation or intoxication); or (d) Glasgow Coma Score in the emergency department of less than 13 (unless due to intubation, sedation, or intoxication); (2) be at least 16 years of age, (3) arrive at the participating TBIMS hospital's emergency department within 72 hours of injury, (4) receive comprehensive rehabilitation in the TBIMS brain injury program, and (5) give written informed consent. Information in the TBIMS-NDB is collected retrospectively from acute care and prospectively during rehabilitation hospitalization, with follow-ups at one, two and five years post-injury, and every five years thereafter. As of September 30, 2010, the TBIMS-NDB contained 10,064 cases, and the rate of successful follow-up over all years (up to 20 years) was 79%.²

The TBIMS-funded centers have been a substantial source of research on acute rehabilitation and long-term outcomes after TBI. As of November 22, 2010, 89 journal publications used TBIMS-NDB data collected from at least two TBIMS centers.² The Model Systems Knowledge Translation Center (MSKTC) at the University of Washington tracks peer-reviewed articles resulting from TBIMS-funded local and collaborative research. Their registry includes 451 such publications,³ though not all of these studies used the TBIMS-NDB. In addition, the TBIMS-NDB is available as a de-identified database for analysis by non-TBIMS researchers. Several TBI-specific measurement tools have been developed by TBIMS investigators and are, or have been, validated using the TBIMS-NDB cohort.⁴

Generalizability of findings from the TBIMS-NDB to all persons 16 years or older receiving acute rehabilitation for TBI has been a concern for almost as long as the data have been reported in published articles. Questions about generalizability arise from both concerns about the inclusion criteria, delineated above, as well as bias that may result from the types of facilities that have competed successfully for TBIMS funding, which have typically been tertiary rehabilitation facilities, often components of academic medical centers, generally

located in urban areas. (A further source of limits to generalizability in the TBIMS-NDB is the effect of non-random influences on subject loss for follow-up interviews, which has been investigated and reported elsewhere.⁵)

In an initial attempt to describe the limits of generalizability due to composition of those treated in TBIMS funded centers, Corrigan and colleagues⁶ compared population-based acute hospitalization data from the CDC-funded South Carolina TBI Follow-up Registry⁷ to the TBIMS-NDB. They observed that the TBIMS cohort experienced more severe TBI, were more likely to have abnormal CT scans and had longer acute hospital lengths of stay (LOS) than the South Carolina cohort. These results were expected, as the TBIMS-NDB is comprised exclusively of patients requiring comprehensive rehabilitation, while the South Carolina cohort represented patients requiring acute hospitalization. Though injury severity primarily distinguished the groups, additional, minor differences in racial and ethnic minority composition and primary payer source were observed that could be attributed to unique characteristics of the South Carolina cohort.

A recent study by Cuthbert and colleagues identified factors that might influence the representativeness of the TBIMS-NDB by examining predictors of discharge disposition, including rehabilitation, for patients in acute care with moderate and severe TBI (a defining characteristic of the TBIMS-NDB).⁸ Analysis of three large datasets that included both TBI severity and discharge disposition showed that the Glasgow Coma Scale (GCS) score and acute hospital LOS accounted for 35% to 44% of the variance when predicting whether a patient would be discharged to home versus to acute rehabilitation or sub-acute care in a nursing facility. Age and gender added from 5% to 8% to this prediction and race/ethnicity and hospitalization payment source added another 2% to 5%. When predicting discharge to rehabilitation versus sub-acute care for those not going home, GCS and LOS accounted for 2% to 4% of the variance, while age and gender added 7% to 31% and race/ethnicity and payment source added 4% to 5%. Across the three datasets, longer LOS, older age, and Caucasian race increased the likelihood of not being discharged home; while the most consistent predictor of discharge to rehabilitation versus sub-acute care was younger age.

A more direct evaluation of the extent to which the TBIMS-NDB represents the U.S. population of older adolescents and adults receiving acute rehabilitation for TBI has become possible following the introduction of the Prospective Payment System (PPS) for Inpatient Rehabilitation Facilities (IRF) in 2001.^{9,10} This public policy change required all IRFs to report Medicare patient diagnostic and functional status information using a standardized methodology. Facilities contract with centralized data repositories to serve as intermediaries with the Center for Medicare and Medicaid Services (CMS). These repositories have required all patients' data to be reported, not just Medicare patients' data, which has created the opportunity for truly comprehensive, national data on persons receiving inpatient rehabilitation. The Uniform Data System for Medical Rehabilitation (UDSMR), which has been in existence since 1987 and is administered by a unit of the University of Buffalo, served approximately 74% of 1,202 IRFs registered by CMS in 2007, the last full year from which data for the current study were drawn.¹¹ The American Medical Rehabilitation Providers Association (AMPRA) started a competing service in 2001, named eRehabData.¹² Like UDSMR, it allows aggregation of data across providers, creation of comparative benchmarks, and other statistics useful in program management. Staff from eRehabData indicated that as of 2007, approximately 18% of U.S. IRFs were included in this dataset (Michael Russell, oral communication, December 2010). PPS payment is based on patients' Case-Mix Group, which is determined by their diagnosis, age and admission Functional Independence Measure (FIM) Motor and Cognitive scores.¹³ Because of the importance of these data collection systems to reimbursement, their data undergo significant scrutiny and, as a result, should be reliable and complete.

Given that a significant proportion of information about the outcomes of rehabilitation for moderate and severe TBI has come from the TBIMS-NDB, and that this dataset is a convenience sample based on the participating centers, it is important for clinicians, researchers and policy makers to appreciate any limits of generalizability to the U.S. TBI rehabilitation population. In this study, we compared nationwide IRF admissions with a primary diagnosis of TBI to subjects in the TBIMS-NDB for an approximate 6-year period from 2002 (soon after adoption of PPS) through the first quarter of Federal Fiscal Year 2008. We hypothesized that the TBIMS-NDB sample is not significantly different from the population of persons 16 years and older in the U.S. receiving rehabilitation with a primary diagnosis of TBI.

METHODS

Data Sources

U.S. TBI Rehabilitation Population—We created a national dataset of rehabilitation patients with a primary diagnosis of TBI by combining records in the UDSMR and eRehabData datasets and selecting cases with age greater than 16 years (the oldest case was 105) admitted between October 1, 2001 and December 31, 2007 (October 1 2007 to December 31, 2007 is the first quarter of the Federal Fiscal Year 2008). Cases were selected if they had an admission class of Initial Rehabilitation (code 1), an Impairment Group Code of 2.21 or 2.22 (Open Traumatic Brain Injury, Closed Traumatic Brain Injury) and either a diagnosis or comorbidity code that met the ICD-9-CM case definition of TBI established by the CDC (800.0-801.9, 803.0-804.9, 850.0-854.1, 959.01).⁴ The final sample included 99,438 cases. In the remainder of this report this dataset is referred to as the “U.S. TBI Rehabilitation” population.

TBIMS-NDB—The TBIMS-NDB sample was limited to cases with a known age and an inpatient rehabilitation admission in the same time frame as was used for selecting UDSMR and eRehabData cases. A total of 4,838 cases were included from the TBIMS-NDB, which consisted of 16 centers during the period of time from which these cases were drawn. Recent data collected by the TBIMS National Data and Statistical Center indicate that 80% of eligible patients are successfully enrolled in the TBIMS-NDB; the others were not approached for logistical reasons or refused participation in the research.¹⁴

Other populations—While comparison of the above datasets was the primary purpose of the current study, information on two additional populations was utilized to provide context. Data on the U.S. population of persons 16 and older discharged alive during the years 2002-2007 from acute hospitals with a diagnosis of TBI and clinical features consistent with moderate, severe or penetrating injuries was provided by the National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.¹⁵ TBI severity was determined using an ICD-9-CM-based algorithm produced by epidemiologists and TBI researchers from the Department of Defense and CDC (Victor Coronado, oral communication, September 2010). In the remainder of this report this dataset is referred to as the “U.S. TBI Acute Care” population.

The U.S. general population age 16 and older as estimated by the U.S. Census Bureau for the years 2002-2007 also was compared to the cohorts of interest.¹⁶ In the remainder of this report this dataset is referred to as the “U.S. Population.”

Variables of Interest

Demographic Factors—Demographic variables of interest were age at rehabilitation admission, gender, marital status and race/ethnicity. Age was grouped in 10-year intervals.

Within marital status, the categories of widowed, separated and divorced occurred infrequently, and were combined into “Previously Married.” Race/ethnicity was categorized as African-American (non-Hispanic), Caucasian (non-Hispanic), Hispanic and “Other,” which included non-Hispanic individuals with a race code indicating Asian, Hawaiian/Pacific Islander, Native American/Aleut and unspecified.

Primary Insurance—Primary payment source for inpatient rehabilitation was classified in six categories: Medicare, Medicaid, Workers Compensation, Self-Pay or No Pay, Private Insurance and Other.

Functional Status—Functional status variables were taken from the FIM completed within 72 hours of rehabilitation admission. The FIM includes 18 items, each of which is scored on a scale ranging from 1 to 7, with higher scores indicating greater independence. FIM Motor and FIM Cognitive subscales are useful in describing two distinct components of functional status.¹⁷ The FIM Motor score is comprised of 13 items, with scores ranging from 13 to 91. The FIM Cognitive score contains 5 items, allowing scores to range from 5 to 35. The FIM Total score was calculated by adding the Motor and Cognitive Subscales, with scores ranging from 18 to 126.¹⁸

Time to Rehabilitation Admission and Rehabilitation Length of Stay—Time to rehabilitation admission was calculated as a continuous variable reflecting the number of days from injury to rehabilitation admission. Rehabilitation length of stay (Rehab-LOS) was calculated as days from inpatient rehabilitation admission to discharge. An interruption in rehabilitation was defined as a period during which a patient was transferred back to acute medical care and later readmitted to rehabilitation. For cases with interruptions of three or less days, Rehab-LOS was calculated as days from admission to discharge, excluding the days of interruption. Cases with an interruption longer than three days had Rehab-LOS calculated as the days from admission to the first day of this interruption. In these cases, the subsequent admission was no longer coded as an “Initial Rehabilitation” and thus was not included in these analyses. Rehab-LOS was used as a continuous and categorical variable. For the latter, stay lengths were categorized in 10-day intervals.

Case-Mix Group (CMG)—CMG classification combines patients who are likely to have similar needs for rehabilitation resources.¹⁹ This system is utilized to derive reimbursement for IRFs paid through Medicare Part A.²⁰ A lower CMG value within the group of TBI CMG codes indicates fewer resources are needed. CMGs were computed using the federal CMG assignment formulas in place at the time of each patient’s admission to rehabilitation. For cases admitted prior to October 1, 2005, CMG was computed using simple additive FIM motor and cognitive scores. CMG’s for cases prior to this date included only groups 201 through 205. Cases admitted on or after October 1, 2005 were assigned to a CMG using the weighted motor score described in the August 15, 2005 Federal Register.²¹ Cases for these years included CMGs 201 through 207.

ANALYSES

Comparisons between the TBIMS-NDB and the U.S. population of patients in rehabilitation for TBI sought to determine similarities and differences on the variables of interest. Due to the sample size, all distributions are statistically significant even though the magnitude of the difference is negligible. Thus, statistical tests of differences were not used; instead, a classification scheme was established *a priori* to structure the interpretation of the magnitude of observed differences. Distribution differences between categorical variables with an absolute value less than 5 percentage points were considered immaterial; those equal to or greater than 5 but less than 10 percentage points were considered *minor* differences; and

those that were 10 percentage points or greater were considered *important* differences. For continuous variables, differences were determined in reference to the standard deviation of the U.S. TBI Rehabilitation population. Differences less than 25% of one standard deviation were considered immaterial; those equal to or greater than 25% but less than 50% of one standard deviation were considered *minor*; and those equal to or greater than 50% *important*.

The U.S. TBI Rehabilitation population was compared to the TBIMS-NDB cohort as both the Total population and the Total without TBIMS-NDB cases. Because all TBIMS centers submit cases to either the UDSMR or eRehabData databases, TBI MS cases were removed from the U.S. TBI rehabilitation population by simple subtraction of the aggregate frequencies. Initial comparisons were computed with and without the TBIMS cases in the U.S TBI rehabilitation population; the latter was done to allow examination of distributions when the samples were completely independent.

RESULTS

The TBIMS-NDB and U.S. TBI Rehabilitation population were compared across each of the 9 categorical and 3 continuous variables of interest (see Table 1). Either minor or important differences were found in at least one level for 7 of the 9 categorical variables, as well as 1 of the 3 continuous variables. Variables with important differences included age (the TBIMS-NDB patients tended to be younger), Rehab-LOS in rehabilitation (fewer patients in the 1 – 9 day category for TBIMS-NDB), Marital Status (more Never Married patients in the TBIMS-NDB), and Primary Payment Source (fewer patients with Medicare and more with Medicaid and Private Insurance in the TBIMS-NDB). The mean difference for Rehab-LOS also showed a difference-minor for the U.S. TBI Rehabilitation population with TBIMS-NDB cases included, but important for the U.S. TBI Rehabilitation population without those cases.

Minor differences were observed for gender (more males in the TBIMS-NDB), race/ethnicity (more African-Americans and fewer Caucasians in the TBIMS-NDB) and FIM Motor (more patients scoring 13 and fewer patients in the 44 – 53 category for the TBIMS-NDB). CMG code and FIM Cognition demonstrated only immaterial differences across all categories; similarly, mean days to rehabilitation and mean FIM Total also showed only immaterial differences.

From these initial comparisons, the largest magnitude differences were in age of the cohorts, and several of the other differences were demographic characteristics that are associated with age (e.g., Gender, Marital Status, Primary Payment Source). Figure 1 shows the extent to which the U.S. TBI Rehabilitation population consisted of a substantially greater proportion of older adults than either the TBIMS-NDB or the U.S. Population. Figure 1 also shows that the greater proportion of patients over age 70 evident for the U.S. TBI Rehabilitation population also characterized the U.S. TBI Acute Care population with moderate, severe or penetrating injuries. Based on this distribution, the datasets were partitioned at age 65, creating datasets comprised of patients younger than 65 years at injury, and another of persons aged 65 years and older. Our pre-established criteria for interpretation of differences were applied to comparisons between the partitioned datasets. Due to the essential equivalence of findings for comparisons when the U.S. TBI Rehabilitation population included or excluded the TBIMS-NDB patients, only the results when TBIMS-NDB patients are included in the national figures reported in Table 2.

Comparisons with and without the TBIMS-NDB are provided as Supplemental Digital Content on the Journal of Head Trauma Rehabilitation website (link to Supplemental Tables 1 and 2).

Sample partitioned at age 65

The differences between cases included in the TBIMS-NDB and the U.S. TBI Rehabilitation population partitioned at age 65 are presented in Table 2. For those under 65, across all variables of interest only 5 had differences. The only important difference was observed for one level of Rehab-LOS (1-9 days)--fewer of these shortest stays occurred in the TBIMS-NDB. Minor differences were observed for age 50-59 (fewer in the TBIMS-NDB), Race/ethnicity (more African Americans in the TBIMS-NDB), Primary Payer Source (more Medicaid in the TBIMS-NDB) and mean Rehab-LOS (longer stays for TBIMS-NDB patients).

For cases 65 years and older, subcategories of age showed both minor and important differences resulting from the TBIMS-NDB having fewer patients aged 80-99. Primary Payment Source had one category of important difference (less Medicare in the TBIMS-NDB) and one category of minor difference (more Private Insurance in the TBIMS-NDB). Rehab-LOS also included one category of important difference (fewer stays 1-9 days for TBIMS-NDB cases) and three categories of minor difference (fewer stays of 10-19 days, but more in the 20-29 and 30-39 day categories for TBIMS-NDB cases). Variables that showed only minor differences included Gender (more males in the TBIMS-NDB), Race/ethnicity (fewer Caucasians in the TBIMS-NDB), FIM Motor (fewer TBIMS-NDB cases in the 44-53 range), FIM Cognitive (more TBIMS-NDB cases in the 6-15 range, fewer in the 26-35 range) and Mean FIM Total (lower scores for the TBIMS-NDB).

Age changes during the decade

To assess differences in the age composition of the TBIMS-NDB and the U.S. TBI Rehabilitation population, we examined trends over time for these cohorts as well as for the total U.S. Population and the U.S. TBI Acute Care population. Persons age 70 and older comprised a disproportionate share of the acute hospital patients with a moderate, severe or penetrating TBI, as well as a disproportionate share of the patients in rehabilitation for TBI. This distribution was less evident in the TBIMS-NDB. Over the 6-year period for which full annual data were available, the general population proportion age 70 and older remained relatively stable, as did the proportion of patients in acute hospitals with a moderate, severe or penetrating TBI, except for a marked increase in 2005, which did not persist over the two subsequent years. In contrast, the proportion of TBI patients 70 and older in rehabilitation increased every year. The TBIMS-NDB showed an increase in the proportion of older adults for the years 2002-2006, but the percentage declined in 2007. The annual growth in older adults in the U.S. TBI Rehabilitation population is inconsistent with both general population trends and acute hospital discharge data.

DISCUSSION

Rehabilitation research seeks to improve the outcomes of individuals with impairments, activity limitations and participation restrictions, directly or indirectly. A substantial portion of TBI rehabilitation research in the United States has been based on the TBIMS-NDB. Supported since the late 1980s by NIDRR, and with contributions from 20 clinical sites that have received Model System grants, the TBIMS-NDB is a unique resource. Many papers, particularly observational studies, on TBI treatment and prognosis for social, medical, economic and psychological recovery have been published that are based on the TBI-NDB. Clinicians are confronted with the questions, "To what degree are the patients included in these TBIMS-NDB analyses similar to my patients? To what degree can the findings be generalized to my next client?" Policymakers and program administrators have similar decisions to make in relation to persons served, or potentially served, in their programs. These questions are not unique to research reports based on the TBIMS-NDB, but need to be

confronted with all research, even that which uses sampling techniques to seek representativeness.²² However, the issue of representativeness is particularly salient for research based on the TBIMS-NDB because funded centers are typically tertiary rehabilitation hospitals or units, often located in large cities with a sizable minority population, or admitting a high percentage of individuals with modest socioeconomic resources. The generalizability of TBIMS-NDB findings to the patients admitted to non-academic, non-metropolitan and for-profit rehabilitation units has not been known.

The results of the current study go far to suggest that during the past decade TBIMS-NDB patients were not dissimilar from individuals 16 years and older with a primary diagnosis of TBI who were admitted to IRF units nationwide. The major difference in the two groups was age, with the TBIMS-NDB cohort not including as many patients age 65 and older as were admitted nationwide. The differences in age composition were even more marked for those 80 or older. There also were differences on several characteristics closely associated with age – having Medicare as a payer, for instance. However, once the database cases were segmented by age, the differences were limited in number and reduced in magnitude.

For the under-65 group, there was only one difference that we considered important: the percent of patients who have a rehabilitation stay of 1-9 days is much larger in the national data than in the TBIMS-NDB. There were only minor differences in the percentage of minorities and the proportion of patients for whom Medicaid was the primary payer, likely linked to the urban location of some TBIMS centers. Differences in the 65 and older group were larger in number, however. The U.S. Rehabilitation population included a greater proportion of adults in the oldest age categories. Important differences in distributions were also found for the percentage with Medicare as the primary payer (fewer in the TBIMS-NDB), and again in the 1-9 days Rehab-LOS category (fewer in the TBIMS-NDB). The older age of the U.S. TBI rehabilitation population and differences in how “primary insurance” is defined may have accounted for the greater proportion of patients with Medicare. There were minor differences in some of the other Rehab-LOS categories, as well as in the percentage of females, non-minorities and persons with private insurance. Lastly, differences were found in FIM Motor (one category) and Cognitive (two categories) functioning, which were linked to dissimilarity in the percent of patients assigned to CMG group 204.

While the results of this study largely support the representativeness of the TBIMS-NDB, the findings also suggest that researchers using the TBIMS-NDB could more closely represent the U.S. TBI rehabilitation population by weighting cases over and under age 65. Less pressing, but potentially defensible, would be to weight cases for Rehab-LOS. Depending on the study, the distributions shown in table 1 and 2 can be used to calculate appropriate weights that would allow a study sample to better match the U.S. TBI rehabilitation population.

The Rehab-LOS discrepancy in both the younger and the older group is puzzling. We completed additional analyses based on finer-grained tabulations (percentage with Rehab-LOS of one day, two days, etc.), but these did not provide clarification. There may be several explanations that cannot be tested based on these data, but which would require collection of additional information. Perhaps the TBIMS-NDB sites do not consent as high a percent of patients who have a short rehabilitation stay, either to be discharged home or to be returned to the acute care hospital from which they were referred. The requirement of informed consent excludes cases from the TBIMS-NDB—recent data indicate that 15% of patients who were otherwise TBIMS-NDB eligible, refused (or their family refused) to be part of the research.¹⁴ For many of the other 5% of otherwise eligible patients who were not enrolled, logistical problems that could not be resolved during the short stay may be an

explanation. While consent can be obtained after discharge from the rehabilitation unit, it is possible that a higher percentage of short-stay patients are not being consented.

Another explanation for fewer short stays in the TBIMS-NDB may be that mild TBI cases are excluded from the TBIMS-NDB based on its inclusion criteria essentially requiring moderate or severe TBI, which is not required for a primary diagnosis in rehabilitation. While it is unlikely that an uncomplicated mild TBI would be sufficient to necessitate inpatient rehabilitation admission, mild TBI associated with other injuries may be. However, for entry in the TBIMS-NDB the brain injury must be the *primary* reason for rehabilitation admission, and it cannot be mild in severity. Presumably, such cases may not require longer Rehab-LOS.

Still another possible explanation for the shorter Rehab-LOS in both the under- and over-65 groups is the fact that the TBIMS rehabilitation units are specialized TBI units, while most of the units and hospitals contributing to UDSMR and eRehabData are not. Even though the admission FIM Motor and FIM Cognitive scores suggest that they admit very similar patients, it may be that the TBIMS preferentially receive referrals of patients with more complicated medical, social, cognitive or behavioral problems, explaining the under-representation of very short stays.

A final caution related to Rehab-LOS is warranted. Researchers using the TBIMS-NDB data to examine Rehab-LOS should take into account that the typical way in which Rehab-LOS is calculated in that dataset was modified to match how Rehab-LOS is calculated for UDSMR and eRehabData. To have comparable Rehab-LOS data, interruptions in TBIMS stays greater than 3 days were treated as two stays--the first with Rehab-LOS from admission to interruption, the second from return to rehabilitation to discharge. For the current study, the return portion was considered a second admission and was not included in the analyses. Only the Rehab-LOS for the initial part of the stay was included in the data analyzed. The TBIMS-NDB Rehab-LOS calculation normally combines the two portions of the stay, counting the days from both. As in the current study, an adjustment in the calculation of Rehab-LOS is necessary anytime TBIMS-NDB data are being compared to data compiled by either UDS or eRehabData.

This study marks the first time data from the rehabilitation intermediaries, UDSMR and eRehabData, have been combined to form a comprehensive picture of patients in rehabilitation for TBI in the U.S. The U.S. TBI Rehabilitation data described in this study comes from at least 92% of the IRF's in the U.S. as of 2007 and likely represents an even higher percentage of all TBI cases in rehabilitation, as the largest programs subscribe to one of these two intermediaries. Knowing the size of the total U.S. TBI annual inpatient rehabilitation population (as of 2008, averaging almost 16,000 per year for persons 16 years old and older) allows estimation of the portion of total TBI rehabilitation patients included in the TBIMS-NDB. Based on the cohorts studied here, patients enrolled in the TBIMS-NDB can be expected to be almost 5% of all, similar-aged patients receiving rehabilitation for TBI. Recent history suggests that less than half of patients with TBI admitted to TBIMS centers are eligible for the TBIMS-NDB; thus, as many as 11% of patients in rehabilitation for TBI are patients at TBIMS facilities.

We also report here estimates from CDC for the number of persons 16 and older discharged alive from acute care with a moderate, severe or penetrating TBI. Comparing these two sources of data for 2002 through 2007, it would appear that only approximately 13% of people discharged alive with these more serious TBIs receive inpatient rehabilitation. This estimate could be lower if the U.S. TBI rehabilitation population reported here contains more than 92% of all cases, the assumption used for this estimation. Another recent study

concluded conservatively that for every one patient 16 years and older with moderate to severe TBI who goes to rehabilitation, three go directly home, suggesting that in the US each year as many as 60,000 late adolescents and adults with moderate to severe TBI may go home directly from an acute care hospital.⁸ Results from the current data would suggest almost twice that estimate--as many as 116,000 Americans over age 15--go directly home from the acute hospital after incurring a moderate, severe or penetrating TBI. Based on previous research, Cuthbert and colleagues observed that a substantial proportion of individuals hospitalized with these more serious injuries will have on-going rehabilitation needs. Whiteneck and colleagues reported from the Colorado TBI Registry and Follow-up System that 49% of Coloradoans hospitalized with a moderate or severe TBI (based on GCS score) had disability at one year post injury, defined as needing assistance on one or more FIM items.²³ Selassie and colleagues estimated that 43.3% of persons hospitalized in South Carolina with *any* TBI severity will experience some disability one year later--a higher rate for those with moderate to severe TBI would be expected.²⁴ As Cuthbert and colleagues speculated, those with moderate to severe injuries who go directly home and do not receive comprehensive rehabilitation may be a previously unrecognized component of the public health burden created by TBI.

While investigating the sources of age differences between the TBIMS-NDB and the U.S. TBI rehabilitation population we found that there is a very large, and growing, proportion of TBI patients over the age of 70 receiving rehabilitation in the U.S. While there has been discussion of the increased number of older adults experiencing TBI and requiring rehabilitation services,^{25,26} the extent of the effect on rehabilitation populations has not received similar attention. The large proportion of adults 70 and older in TBI rehabilitation closely paralleled the age composition of persons discharged alive from acute care with moderate, severe or penetrating TBI. Why older adults are so disproportionately represented in both settings deserves further study. Factors that might be explored include increasingly active lifestyles among older adults who concurrently have greater vulnerability for injury, or improved survival rates due to emergency medical and/or neurosurgical practices. We also observed that the proportion of older adults in the U.S. TBI rehabilitation population increased every year from 2001 through 2007. This pattern was not evident in any of the other cohorts, including the U.S. TBI acute care population. Whether clinical practice or administrative procedures account for this pattern is not known. The number of for-profit, rural, and small IRFs has increased since the mid-1990's,²⁷ and these facilities tend to serve more older adults with Medicare coverage. The "75% rule"²⁸ began to influence rehabilitation during the period studied; which might encourage "diagnosis creep" favoring TBI as a primary diagnosis even though the TBI may not be the most prominent etiology of reduced function. It is possible that some of those in the oldest age categories for the U.S. TBI rehabilitation population incurred less severe TBI, thus excluding them from the TBI Model Systems. This observation is speculative as data on the U.S. TBI rehabilitation population does not include injury severity. Again, further research is needed to clarify these influences.

Limitations

This study has several potential limitations. Our criteria for what constitutes a minor or important difference may have been too lenient, classifying too many differences between the TBIMS-NDB and the national population of TBI rehabilitation admissions as "immaterial." The data provided in the tables allow readers to apply their own criteria to determine similarity vs. difference.

The variables available from the national population of TBI rehabilitation admissions and TBIMS-NDB limit the analyses that can be done. The TBIMS-NDB contains many data elements not contained in UDSMR and eRehabData, including potentially important

parameters such as pre-injury functional status, prior substance misuse, co-occurring injuries, length of post-traumatic amnesia or cognitive performance post-injury. In addition, there are many other characteristics (e.g., body mass index; administration of specific drugs, therapies received) that are not reported in either database, but could differ between the samples and be relevant to rehabilitation interventions and their outcomes. This issue is not a shortcoming of the analysis per se, but a warning that “no difference” or “minor difference” findings are limited to a small set of key variables.

Another limitation is that many published articles based on the TBIMS-NDB do not use the entire database, but apply additional selection criteria of relevance to a particular research question. The representativeness of the TBIMS-NDB demonstrated in this study may not necessarily apply to all subsamples.

While the U.S. TBI rehabilitation dataset accounted for at least 92% of all patients 16 and older in rehabilitation for a primary diagnosis of TBI, there is a possibility that the remaining cases differ enough to change some of the findings. Lastly, our finding that in the U.S. TBI rehabilitation population the percentage of patients aged 70 or higher increased steadily over the years studied, but that there was no parallel increase among TBIMS patients, should be a reminder that any ability to generalize from TBIMS reports to all US TBI rehabilitation patients cannot be assumed to be permanent; distributions can change. The analyses reported here should be repeated every 5 or 10 years to monitor the continued representativeness of the TBIMS-NDB.

Summary

These results provide substantial empirical evidence that the TBIMS-NDB is representative of patients receiving inpatient rehabilitation for TBI in the United States during this past decade. Researchers utilizing the TBIMS-NDB should consider whether they want to account statistically for the lower percentage of patients over age 65 or those with stays less than 10 days. This study also underscores the increasing proportion of older adults both surviving severe TBI and receiving rehabilitation. Implications for clinical care, healthcare delivery systems and public policy should be given greater attention as we believe this shift in population characteristics is not being widely discussed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This research was supported by supplemental grant funding to the Traumatic Brain Injury Model Systems National Data and Statistical Center from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education (grant no. H133A060038), as well as TBI Model System Center grants to Craig Hospital (H133A070022), Ohio State University (H133A070029), Mount Sinai School of Medicine (H133A070033) and the Rehabilitation Institute of Chicago (H133A080045). However, the contents do not necessarily represent the policy of the Department of Education, and the reader should not assume endorsement by the Federal Government. This article does not reflect the official policy or opinions of the Centers for Disease Control and Prevention (CDC) or the U.S. Department of Health and Human Services (HHS) and does not constitute an endorsement of the individuals or their programs—by CDC, HHS, or other components of the federal government—and none should be inferred.

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Figure 1.

Age distributions for the TBI Model Systems National Database, the U.S. Population of Adults in Rehabilitation with a primary diagnosis of TBI, U.S. Acute Care admissions discharged alive with moderate, severe or penetrating TBI, and the U.S. Population.

Figure 2.

Changes in the age distribution for the U.S. general population (2002-2007), acute care admissions discharged alive with a moderate, severe or penetrating TBI (2002-2007), TBI Model Systems National Database (2002-2008) and the U.S. population admitted to rehabilitation with a primary diagnosis of TBI (2002-2008).

Table 1

Comparison of the U.S. Population of Adults in Rehabilitation for a Primary Diagnosis of TBI to the TBI Model Systems National Database

	U.S. minus TBIMS Difference			
	U.S. TBI Rehab population	U.S. TBI Rehab without TBIMS	TBIMS	U.S. includes TBIMS U.S. excludes TBIMS
Age				
16-19	6.9%	6.6%	13.2%	-6.3%* -6.6%*
20-29	14.3%	13.6%	26.3%	-12.0%† -12.6%†
30-39	9.1%	8.8%	14.4%	-5.3%* -5.5%*
40-49	11.5%	11.2%	17.3%	-5.9%* -6.2%*
50-59	10.7%	10.6%	12.0%	-1.3% -1.3%
60-69	10.2%	10.3%	7.2%	3.0% 3.2%
70-79	16.4%	17.0%	5.8%	10.6%† 11.1%†
80-89	17.8%	18.5%	3.6%	14.2%† 14.9%†
90-99	3.1%	3.3%	0.3%	2.8% 3.0%
100 & Older	0.1%	0.1%	0.0%	0.1% 0.1%
Missing	0.0%	0.0%	0.0%	
Gender				
Male	65.2%	64.8%	73.5%	-8.2%* -8.7%*
Female	34.7%	35.2%	26.5%	8.2%* 8.6%*
Missing	0.0%	0.0%	0.0%	
Marital Status				
Never married	32.7%	32.0%	46.8%	-14.1%† -14.8%†
Married	40.2%	40.5%	33.0%	7.2%* 7.6%*
Previously Married	25.2%	25.5%	20.1%	5.1%* 5.4%*
Missing	1.9%	2.0%	0.1%	

	U.S. minus TBIMS Difference			
	U.S. TBI Rehab population	U.S. TBI Rehab without TBIMS	TBIMS	U.S. includes TBIMS U.S. excludes TBIMS
Race/Ethnicity				
Caucasian	77.5%	77.9%	70.6%	7.0%* 7.3%*
African American	9.2%	8.8%	17.6%	-8.4%* -8.8%*
Hispanic	6.9%	6.9%	8.2%	-1.3% -1.4%
Other	5.0%	5.1%	3.6%	1.4% 1.4%
Missing	1.3%	1.4%	0.0%	
Primary Payment Source				
Private Insurance	35.9%	35.3%	47.4%	-11.5%† -12.1%†
Medicare	42.1%	43.6%	12.5%	29.6%† 31.1%†
Medicaid	9.7%	9.1%	21.2%	-11.6%† -12.2%†
Workers Comp	3.6%	3.6%	5.3%	-1.7% -1.8%
elf- or No Pay	5.9%	5.8%	8.8%	-2.9% -3.1%
Other	2.8%	2.8%	2.8%	0.0% 0.0%
Missing	0.0%	0.0%	1.9%	
Days to rehabilitation admission				
Mean (SD)	19.3 (26.5)	18.2 (26.2)	20.5 (16.3)	-1.2 -2.3
FIM Total at admission				
Mean (SD)	55.5 (22.4)	53.0 (21.1)	51.7 (23.9)	3.8 1.3
FIM Motor at admission				
13	8.3%	8.0%	13.4%	-5.2%* -5.4%*
14 through 23	16.1%	16.0%	18.9%	-2.7% -2.9%
24 through 33	16.0%	16.0%	15.1%	0.9% 1.0%
34 through 43	19.1%	19.3%	15.4%	3.7% 3.9%
44 through 53	21.0%	21.3%	15.3%	5.7%* 6.0%*

	U.S. minus TBIMS Difference				
	U.S. TBI Rehab population	U.S. TBI Rehab without TBIMS	TBIMS	U.S. includes TBIMS	U.S. excludes TBIMS
54 through 63	13.4%	13.5%	11.3%	2.1%	2.2%
64 through 73	4.5%	4.5%	5.2%	-0.7%	-0.7%
74 through 83	1.3%	1.2%	1.7%	-0.5%	-0.5%
84 through 91	0.4%	0.4%	0.4%	0.0%	0.0%
Missing	0.0%	0.0%	3.3%		
FIM Cognitive at admission					
5	9.7%	9.5%	13.3%	-3.7%	-3.8%
6 through 15	34.4%	34.4%	35.6%	-1.2%	-1.2%
16 through 25	37.9%	38.0%	36.9%	1.1%	1.1%
26 through 35	18.0%	18.2%	13.4%	4.6%	4.9%
Missing	0.0%	0.0%	0.9%		
Case Mix Group					
201	6.6%	6.5%	7.5%	-0.9%	-1.0%
202	7.7%	7.9%	4.6%	3.1%	3.3%
203	20.0%	19.9%	21.3%	-1.3%	-1.3%
204	13.9%	14.1%	10.4%	3.5%	3.7%
205	31.4%	31.3%	33.5%	-2.2%	-2.3%
206	5.8%	5.8%	5.6%	0.2%	0.2%
207	12.6%	12.5%	15.1%	-2.5%	-2.6%
Missing	2.1%	2.1%	2.0%		
Rehabilitation LOS (minus interr					
ptions)					
1 through 9	28.7%	29.2%	18.0%	10.7% [†]	11.3% [†]
10 through 19	38.8%	39.1%	34.3%	4.5%	4.8%
20 through 29	19.0%	18.8%	22.2%	-3.2%	-3.3%
30 through 39	6.8%	6.6%	10.7%	-3.9%	-4.1%
40 through 49	2.9%	2.8%	5.3%	-2.4%	-2.5%

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U.S. minus TBIMS Difference				
	U.S. TBI Rehab population	U.S. TBI Rehab without TBIMS	TBIMS	U.S. includes TBIMS U.S. excludes TBIMS
50 through 59	1.4%	1.3%	3.2%	-1.9% -2.0%
60 through 69	0.8%	0.8%	1.9%	-1.1% -1.2%
70 through 79	0.5%	0.5%	1.2%	-0.7% -0.7%
80 through 89	0.3%	0.3%	0.9%	-0.6% -0.6%
90 through 99	0.2%	0.2%	0.6%	-0.4% -0.4%
100 +	0.5%	0.5%	1.5%	-1.0% -1.0%
Missing	0.0%	0.0%	0.1%	
Mean (SD)	18.1 (14.9)	16.5 (13.2)	24.8 (23.8)	-6.7 ^{**} -8.3 [‡]

Rehab = Rehabilitation, TBIMS = Traumatic Brain Injury Model Systems National Database, FIM = Functional Independence Measure, C = FIM Cognitive, M = FIM Motor, LOS = length of stay

^{*} indicates differences within categorical variables with an absolute value 5% but < 10%

[‡] indicates differences within categorical variables with an absolute value 10%

^{**} indicates differences 25% but < 50% of 1 SD for the U.S. population

[‡] indicates differences 50% of 1 SD for the U.S. population

Table 2

Comparison of the U.S. Population of Adults in Rehabilitation for a Primary Diagnosis of TBI to the TBI Model Systems National Database Stratified by Age. (U.S. population includes the TBIMS cases.)

	< 65 years old			65 + years old		
	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference
Age						
16-19	12.1%	15.1%	-3.0%	--	--	--
20-29	25.0%	30.1%	-4.9%	--	--	--
30-39	15.9%	16.5%	-0.6%	--	--	--
40-49	20.1%	19.9%	0.2%	--	--	--
50-59	18.8%	13.7%	5.1% *	--	--	--
60-64	8.2%	4.6%	3.6%	--	--	--
65-69	--	--	--	12.9%	24.5%	-11.6% †
70-79	--	--	--	38.3%	45.3%	-7.0% *
80-89	--	--	--	41.4%	28.0%	13.4% †
90-99	--	--	--	7.2%	2.2%	5.0% *
100 & Older	--	--	--	0.2%	0.0%	0.2%
Missing	0.0%	0.0%		0.0%	0.0%	
Gender						
Male	74.5%	75.7%	-1.2%	52.9%	58.6%	-5.7% *
Female	25.5%	24.3%	1.2%	47.1%	41.4%	5.7% *
Missing	0.0%	0.0%		0.0%	0.0%	
Marital Status						
Never married	51.2%	52.7%	-1.5%	8.2%	7.2%	1.0%
Married	32.9%	30.1%	2.8%	49.9%	52.3%	-2.5%
Previously Married	13.7%	17.1%	-3.3%	40.4%	40.3%	0.1%
Missing	2.2%	0.1%		1.5%	0.2%	
Race/Ethnicity						

	< 65 years old			65 + years old		
	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference
Caucasian	72.0%	69.2%	2.8%	84.9%	79.7%	5.3% *
African American	12.2%	18.7%	-6.5% *	5.3%	10.1%	-4.9%
Hispanic	9.1%	8.5%	0.5%	4.0%	5.9%	-1.9%
Other	5.2%	3.5%	1.7%	4.7%	4.3%	0.4%
Missing	1.5%	0.0%		1.1%	0.0%	
Primary Payment Source						
Private Insurance	55.8%	51.7%	4.0%	9.5%	18.6%	-9.1% *
Medicare	7.3%	3.8%	3.5%	88.3%	71.4%	17.1% †
Medicaid	16.4%	23.8%	-7.3% *	0.7%	4.2%	-3.5%
Workers Comp	5.9%	5.9%	0.0%	0.7%	1.8%	-1.1%
Self- or No Pay	10.2%	10.0%	0.2%	0.2%	1.0%	-0.8%
Other	4.5%	3.1%	1.4%	0.6%	1.0%	-0.4%
Missing	0.0%	0.0%		0.0%	2.2%	
Days to rehabilitation admission						
Mean (SD)	23.8 (31.8)	21.4 (16.7)	2.4	13.5 (19.6)	14.6 (13.5)	-1.2
FIM Total at admission						
Mean (SD)	55.2 (24.4)	51.9 (24.5)	3.3	55.8 (19.7)	50.6 (20.1)	5.3 **
FIM Motor at admission						
13	11.0%	14.2%	-3.2%	4.6%	8.0%	-3.4%
14 through 23	16.3%	18.6%	-2.4%	15.9%	20.3%	-4.5%
24 through 33	12.9%	13.8%	-0.8%	20.0%	23.8%	-3.9%
34 through 43	15.4%	14.8%	0.6%	24.0%	19.2%	4.9%
44 through 53	19.4%	15.4%	4.0%	23.1%	14.6%	8.7% *
54 through 63	15.6%	11.7%	3.9%	10.4%	8.2%	2.2%
64 through 73	6.7%	5.6%	1.1%	1.7%	2.7%	-1.1%
74 through 83	2.1%	2.0%	0.1%	0.2%	0.0%	0.2%

	< 65 years old			65 + years old		
	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference
84 through 91	0.7%	0.5%	0.2%	0.0%	0.0%	0.0%
Missing	0.0%	3.3%		0.0%	3.2%	
FIM Cognitive at admission						
5	12.5%	14.2%	-1.7%	5.9%	7.4%	-1.5%
6 through 15	38.0%	35.5%	2.5%	29.7%	36.5%	-6.9% *
16 through 25	34.9%	36.0%	-1.0%	41.9%	42.9%	-1.0%
26 through 35	14.6%	13.4%	1.2%	22.5%	13.1%	9.5% *
Missing	0.0%	1.0%		0.0%	0.2%	
Case Mix Group						
201	7.9%	8.0%	0.0%	4.8%	4.5%	0.4%
202	5.8%	4.4%	1.4%	10.2%	5.6%	4.7%
203	24.9%	22.2%	2.7%	13.5%	15.0%	-1.6%
204	11.9%	10.2%	1.7%	16.5%	11.4%	5.2% *
205	30.3%	33.3%	-3.0%	32.8%	35.0%	-2.2%
206	4.4%	4.8%	-0.4%	7.7%	11.4%	-3.8%
207	12.2%	15.0%	-2.8%	13.0%	15.4%	-2.4%
Missing	2.5%	2.1%		1.5%	1.8%	
Rehabilitation LOS days (minus interruptions)						
1 through 9	29.3%	18.4%	10.9%	27.9%	15.4%	12.7% †
10 through 19	33.7%	34.0%	-0.2%	45.6%	36.5%	9.2% *
20 through 29	18.5%	21.7%	-3.2%	19.6%	25.1%	-5.6% *
30 through 39	8.2%	10.6%	-2.4%	4.9%	11.4%	-6.5% *
40 through 49	4.2%	5.4%	-1.2%	1.2%	4.8%	-3.6%
50 through 59	2.1%	3.3%	-1.2%	0.4%	2.9%	-2.5%
60 through 69	1.3%	2.1%	-0.8%	0.2%	1.0%	-0.8%
70 through 79	0.8%	1.2%	-0.4%	0.1%	1.1%	-1.1%

	< 65 years old			65 + years old		
	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference	U.S. TBI Rehab population	TBIMS	U.S. minus TBIMS Difference
80 through 89	0.6%	1.0%	-0.5%	0.0%	0.3%	-0.3%
90 through 99	0.4%	0.7%	-0.3%	0.0%	0.2%	-0.2%
100 +	0.9%	1.6%	-0.7%	0.0%	0.8%	-0.8%
Missing	0.0%	0.1%		0.0%	0.6%	
Mean (SD)	20.2 (19.1)	25.1 (24.7)	-4.9 **	15.4 (9.3)	23.0 (17.9)	-7.7 ‡

Rehab = Rehabilitation, TBIMS = Traumatic Brain Injury Model Systems National Database, FIM = Functional Independence Measure, C = FIM Cognitive, M = FIM Motor, LOS = length of stay

* indicates differences within categorical variables with an absolute value 5% but < 10%

‡ indicates differences within categorical variables with an absolute value 10%

** indicates differences 25% but < 50% of 1 SD for the U.S. population

‡ indicates differences = 50% of 1 SD for the U.S. population