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ORIGINAL ARTICLE

Long-Term Disability and Survival in Traumatic Brain Injury: Results From the National Institute on Disability and Rehabilitation Research Model Systems

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Abstract

Objectives: To document long-term survival in 1-year survivors of traumatic brain injury (TBI); to compare the use of the Disability Rating Scale (DRS) and FIM as factors in the estimation of survival probabilities; and to investigate the effect of time since injury and secular trends in mortality.

Design: Cohort study of 1-year survivors of TBI followed up to 20 years postinjury. Statistical methods include standardized mortality ratio, Kaplan-Meier survival curve, proportional hazards regression, and person-year logistic regression.

Setting: Postdischarge from rehabilitation units.

Participants: Population-based sample of persons (N=7228) who were admitted to a TBI Model Systems facility and survived at least 1 year postinjury. These persons contributed 32,505 person-years, with 537 deaths, over the 1989 to 2011 study period.

Interventions: Not applicable.

Main Outcome Measure: Survival.

Results: Survival was poorer than that of the general population (standardized mortality ratio=2.1; 95% confidence interval, 1.9−2.3). Age, sex, and functional disability were significant risk factors for mortality ($P<.001$). FIM- and DRS-based proportional hazards survival models had comparable predictive performance (C index: .80 vs .80; Akaike information criterion: 11,005 vs 11,015). Time since injury and current calendar year were not significant predictors of long-term survival (both $P>.05$).

Conclusions: Long-term survival prognosis in TBI depends on age, sex, and disability. FIM and DRS are useful prognostic measures with comparable statistical performance. Age- and disability-specific mortality rates in TBI have not declined over the last 20 years. A survival prognosis calculator is available online (http://www.LifeExpectancy.org/tbims.shtml).

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Clinicians and other professionals are often asked to comment on survival prognosis of persons who have suffered traumatic brain injury (TBI). The survival prognosis for an individual patient may be requested by family members for personal reasons and is a necessary component in the development of a life care plan. In personal injury litigation matters, the survival prognosis often plays a central role in the determination of the size of an award. Whatever the context, responsible practice dictates that prognosis opinions should be based on the best available evidence, as opposed to anecdote or speculation.

Over the last 20 years, the evidence on survival after moderate to severe TBI has grown with long-term follow-up studies of large cohorts.[1-21] Examples include the United States National Institute on Disability and Rehabilitation Research-funded TBI Model Systems National Database,[1,2,4,19-21] the Colorado inpatient rehabilitation study of Harrison-Felix et al,[3] the California-based

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studies of Strauss et al,[5-9] and the Australian studies of Baguley et al.[10-12] These studies are consistent in the identification of age and severity of functional disability as the most important clinical predictors of long-term survival. Few of these studies, however, provide estimates of survival probabilities that can be used in prognoses for individual patients.

In this article we use data from the TBI Model Systems National Database to compare the Disability Rating Scale (DRS)[22] with the FIM[23] regarding the prediction of survival probabilities in 1-year survivors of TBI. We distill the results into a practical tool to produce age- and sex-specific survival curves for persons with particular levels of disability. We also investigate whether time since injury has an effect on mortality. Finally, to determine whether our findings apply to contemporary TBI cases, we examine the issue of secular trend, which asks whether survival is better today than in the past.

Methods

Participants and inclusion criteria

This study was approved by the Hospital Corporation of America-HealthOne Institutional Review Board at Craig Hospital. Study participants were persons with TBI who were admitted to 1 of 20 TBI Model Systems hospitals and who contributed data to the National Institute on Disability and Rehabilitation Research TBI Model Systems National Database. Data collection protocols have been described previously.[21] The definition of TBI used in the database is damage to brain tissue caused by an external mechanical force as evidenced by medically documented loss of consciousness or posttraumatic amnesia (PTA) due to brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination.[21]

In addition, subjects included in the database must (1) meet at least 1 of the following criteria for moderate to severe TBI: posttraumatic amnesia >24 hours, trauma-related intracranial neuroimaging abnormalities, loss of consciousness exceeding 30 minutes, a Glasgow Coma Scale score in the emergency department of <13 (unless because of intubation, sedation, or intoxication); (2) be ≥16 years of age at the time of injury; (3) present to the TBI Model System's acute care hospital within 72 hours of injury; (4) receive both acute hospital care and comprehensive rehabilitation in a designated brain injury inpatient unit within the TBI Model System; and (5) provide informed consent to participate or have a proxy provide consent.[24] Each subject contributes information on functional status at rehabilitation admission and discharge, and at long-term follow-up evaluations typically performed at 1, 2, 5, 10, 15, and 20 years postinjury. Details on the follow-up protocol are fully documented in previous work.[21]

Our sample was composed of persons in the TBI Model Systems National Database injured between 1988 and 2010 who provided a complete follow-up assessment at 1-year evaluation or later, as of March 2011. The earliest complete follow-up evaluation for each individual was used in the construction of the survival prognosis models. We retained all complete follow-up evaluations to construct a person-year data set for use in the analysis of time since injury effects and secular trends. Persons without any complete follow-up assessments were excluded from analysis.

List of abbreviations:

AIC	**Akaike information criterion**
CI	**confidence interval**
DRS	**Disability Rating Scale**
SMR	**standardized mortality ratio**
SSDI	**Social Security Death Index**
TBI	**traumatic brain injury**

Vital status

Vital status of each participant was ascertained using the Social Security Death Index (SSDI) just prior to follow-up interviews. SSDI matching has been shown to have a sensitivity of 89% and a specificity of 100% in the TBI Model Systems population.[1] Vital status of persons without an SSDI was confirmed by phone interview. Participants were assumed alive if (1) there was no SSDI match, and (2) the phone interview did not indicate that the participant had died. Those who did not have an SSDI match but were confirmed dead by phone interview without a known date of death were assumed to have died midway between the last 2 attempted phone interviews.

Risk factors

The risk factors considered in our analyses included age, sex, time since injury, functional disability, and calendar year. Disability was measured with the DRS[22] and FIM[23] during follow-up evaluations at 1 year after injury or later. Missing data on disability beyond the first year postinjury were imputed with the last observation carried forward.

In brief, the FIM is a validated measure of dependence in 18 domains (13 motor and 5 cognitive). Each domain is scored on a 1- to 7-point scale, where 1 indicates complete dependence and 7 indicates complete independence. Thus, the minimum FIM score is 18, and the maximum is 126.

DRS items address impairment (eye opening, communication ability, motor response), disability (cognitive abilities for feeding, toileting, and grooming), and handicap (level of functioning and employability). Each item is typically evaluated on an integer point scale; however, for most study years (1994−2010), a 0.5 rating system was adopted for the last 5 items. Total scores range from 0 to 29, with a higher score signifying greater disability. DRS scores of 22 or more are typically associated with the minimally conscious or a vegetative state.

Statistical analysis

The expected age- and sex-matched survival in the U.S. general population was computed based on national life tables.[25] Standardized mortality ratios (SMRs) were computed with stratification on time since injury, age, and calendar year. In brief, the SMR is equal to the number of observed deaths in our cohort divided by the number of deaths expected based on age- and sex-matched mortality rates in the general population.

Survival was modeled with proportional hazards regression models[26] adjusted for age, sex, and severity of functional disability assessed with the DRS and FIM. The models were compared with respect to the C index[27] and Akaike information criterion (AIC).[28] In brief, the C index is an indicator of how well the model ranks survival times from longest to shortest. A C index of 1 indicates a perfect ranking of all survival times, whereas a C index of 0.5 indicates a ranking no better than chance. The AIC is a likelihood-based model selection statistic with lower values indicating a more consistent fit of the underlying data.

For practical purposes we defined a survival prognosis model based on a patient's specific level of care needs. This model used a simple patient grouping scheme (fig 1A) derived from the level of functioning DRS item, a subscale with values from 0 to 5. Our practical model contained 4 groups. The criteria for these groups were: (1) largely independent, minimal assistance at most (level of functioning <1); (2) requires mechanical aids or assistance with some activities (1 ≤ level of functioning < 3); (3) requires assistance with all activities, 24-hour home care (3 ≤ level of functioning < 5); and (4) total dependence, requires 24-hour nursing care (level of functioning = 5).

The effects of time since injury and secular trend were estimated with a logistic regression model applied to person-year data with time-dependent covariates.[29] Here, the dependent variable was a binary indicator of whether the person died during the 1-year interval. The independent variables were sex and time-dependent values of age, functional disability, time since injury, and calendar year. This method is preferred because it allows a hypothesis testing for both time since injury effects and secular trends while controlling for the effects of age and functional disability. Data were analyzed with SAS version 9.12[a] and R version 2.15[b] software.

Results

Descriptive statistics

There were 7228 persons (73% men) who collectively contributed 15,516 follow-up evaluations at ≥1 year postinjury. The vast majority (89%) of these individuals provided their first complete follow-up evaluation at 1 year postinjury; 7% had their earliest complete follow-up evaluation at 2 years postinjury; and 3% had their earliest complete follow-up evaluation within 5 years. The remaining 1% completed their first follow-up evaluation at ≥5 years after injury. Table 1 provides a summary of demographic and injury factors for the study participants. The mean age ± SD at injury was 38.9±17.9 years. The median year of injury was 2004, which reflects increasing TBI Model Systems enrollment throughout the study period. There were 32,505 person-years of follow-up and 537 deaths (508 SSDI matches and 29 confirmed with phone interview without SSDI match), for an overall mortality rate of 16.5 deaths per 1000 persons per year.

The 1-year postinjury FIM and DRS scores had highly skewed distributions. The mean FIM score ± SD was 114.0±19.6. Feeding (mean ± SD, 6.6±1.0) was the physical domain with the highest level of independence, and stair climbing (mean ± SD, 5.9±1.7) was the physical domain with the lowest. In cognitive domains, memory (mean ± SD, 5.7±1.4) and problem solving (mean ± SD, 5.9±1.5) were the least independent areas.

The mean DRS score ± SD was 2.8±3.5. The greatest levels of disability were observed in the handicap items: employability (mean ± SD, 1.3±1.1) and level of functioning (mean ± SD, 1.0±1.3). Some 16% of the study participants achieved a fully independent score of 126 out of 126 on the FIM, and 25% had a DRS score of 0 out of 29. Conversely, there were very few individuals at the most severe end of the disability spectrum. Only 1% had a total FIM score of 18, that is, a bottom score on every domain; fewer than 1% had a DRS exceeding 22, which is typically associated with a minimally conscious or vegetative state.

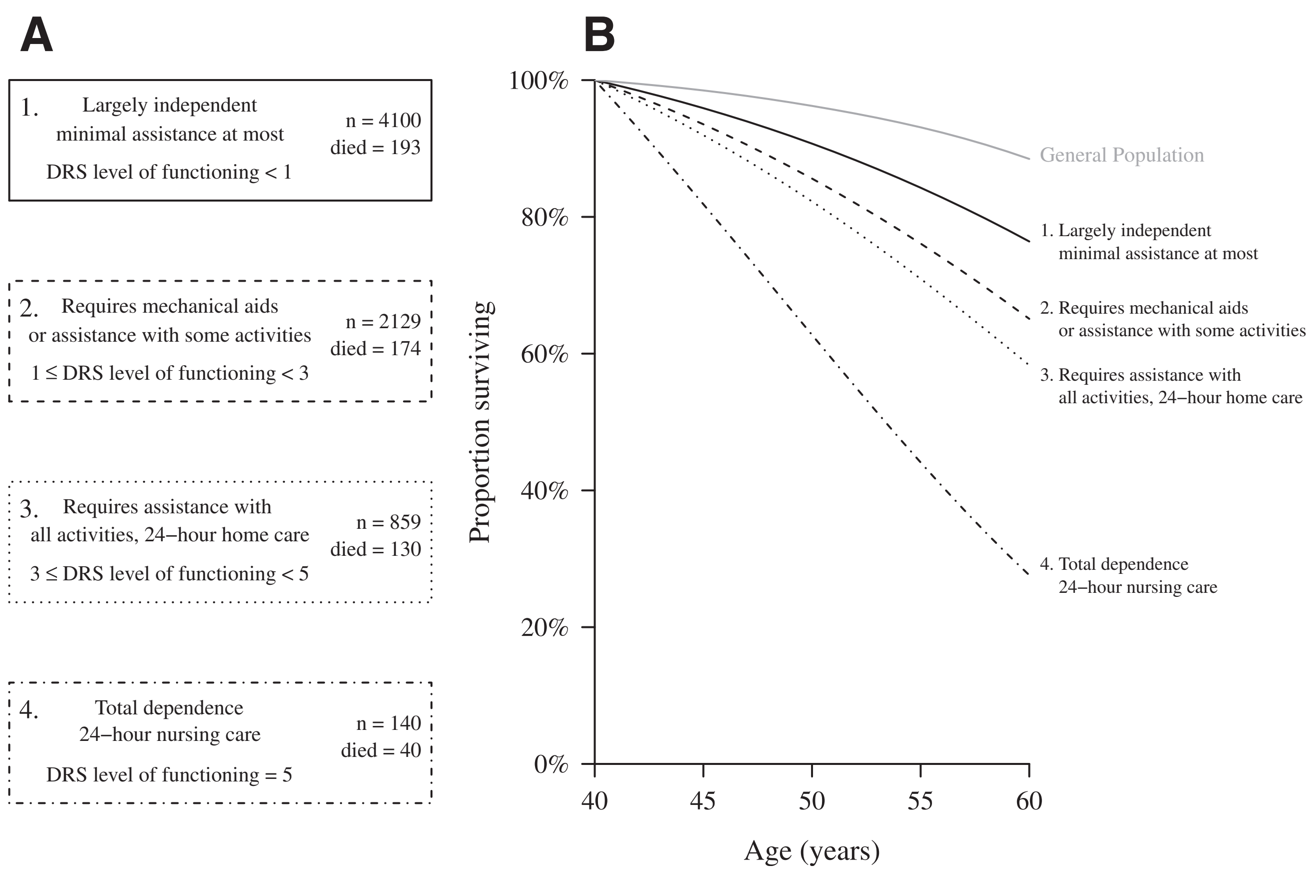

Fig 1 Comparison groups (A) and survival prognoses for a man aged 40 years (B).

Table 1 Participant characteristics

Characteristic	Value
Age at injury (y)	38.9±17.9
Male	73
Race	
White	70
Black	21
Asian/Hispanic/other	9
Preinjury education	
Did not complete high school	41
High school graduate, no college	22
Some college or beyond	36
Missing educational attainment	2
Preinjury employment	
Employed	66
Student	8
Retired	12
Unemployed	14
Preinjury marital status	
Single	49
Married	31
Divorced/separated/widowed	20
Preinjury illicit drug use*	
Yes	22
No	73
Unknown/missing	5
Alcohol in blood at injury	54
Etiology	
Motor vehicle collision	63
Fall	22
Sports	2
Violence	13
Other/unknown	<1
Acute hospital payer	
Health Maintenance Organization/Preferred Provider Organization/private insurance	43
Medicaid	23
Medicare	10
Worker's compensation	6
No fault insurance	6
Other/unknown	12
Intubation at admission	36
Induced coma at admission	21
GCS at admission†	9.2±4.4
Posttraumatic amnesia (d)	25.1±22.7
First complete follow-up	
1y postinjury	89
2–4y postinjury	10
5–20y postinjury	1
Long-term total DRS score‡	2.8±3.5
Long-term total FIM score‡	114.0±19.6

NOTE. Categorical values reported as %; continuous values reported as mean ± SD.
Abbreviation: GCS, Glasgow Coma Scale.
* Based on data collected in years 1997 and later.
† Excludes 21% who were put into chemically induced coma and 2% with missing/unknown values.
‡ First complete assessment at long-term follow-up evaluation.

The DRS and FIM were highly inversely correlated (Spearman $\rho=-.81$, $P<.001$). For example, 98% of persons with a DRS score of 0 had a FIM score of ≥120, and 97% of persons with FIM scores of 126 had a DRS score of ≤2. Of persons with a DRS score in the range of 20 to 29, 81% had a FIM score of 18, the lowest possible.

Comparisons with general population survival

The Kaplan-Meier survival estimate at 20 years postinjury in the TBI population was 70% compared with the 80% expected under age- and sex-matched U.S. general population mortality rates. The overall SMR was 2.1 (95% confidence interval [CI], 1.9–2.3). The SMR declined with increasing age: 3.3 (95% CI, 2.6–4.1) at ages 20 to 40 versus 1.3 (95% CI, 1.1–1.6) at ages >80 years. The SMR did not vary significantly with time since injury. The SMR was somewhat lower during years 2000 to 2009 (SMR=2.0; 95% CI, 1.9–2.2) as compared with the period from 1990 to 1999 (SMR=2.7; 95% CI, 2.1–3.5).

Survival prognosis models: DRS versus FIM

The simple proportional hazards regression model, which included only terms for age and sex, achieved a C index ± SE of .79±.01 and an AIC of 11,136. Models that included the total DRS and FIM scores both achieved C indices ± SE of .80±.01. The AIC of the DRS-based model was somewhat lower than that of the FIM-based model (AIC: 11,005 vs 11,015). The relations between mortality rates and the quintiles of DRS and FIM were nonlinear (table 2). The crude death rates were broadly similar for successive quintiles of DRS and FIM. After adjustment for age and sex, the hazard ratios for the most severely disabled quintile compared with the least disabled quintile were 4.1 in the DRS-based model versus 2.9 in the FIM-based model. The hazard ratio for a DRS score of 29 (most severe) relative to a score of 0 (least severe) was 38, whereas the hazard ratio for a FIM score of 18 (most severe) relative to a score of 126 (least severe) was only 10.

The proposed practical prognosis model achieved a C index ± SE of .80±.01 and an AIC of 11,040. Under this model, mortality rates increased by 5.8% for every additional year of age. The hazard ratios for the 4 comparison groups were the following: (1) 1.0 (reference), (2) 1.6, (3) 3.4, and (4) 8.2. Men in the first 2 groups had mortality rates that were 71% higher than those of women in these groups. Figure 1B presents model-based survival curves for 40-year-old men who have survived at least 1 year postinjury. The estimated survival curve for those with minimal disability was worse than that of typical 40-year-old men in the general population. For those at the severe end of the spectrum, who required 24-hour nursing care, the estimated median survival time was only 13.4 additional years, that is, until age 53.4.

Time since injury and secular trend: person-year analysis

No significant temporal effects were observed (table 3). With adjustment for age, sex, and severity of disability, the logistic person-year analysis indicated that time since injury was not a significant risk factor for mortality ($P>.05$). The same person-year regression analysis also indicated that mortality rates during the 2000s were not significantly different from those in the 1990s ($P>.05$).

Table 2 Death rates and hazard ratios by DRS and FIM

	DRS			FIM		
Severity Quintile	Total Score	Death Rate*	Hazard Ratio†	Total Score	Death Rate*	Hazard Ratio†
1st (least severe)	0	6.3	1.0 (reference)	126	8.3	1.0 (reference)
2nd	0.5–1.0	9.1	1.4	124–125	8.6	1.0
3rd	1.5–2.5	15.5	2.1	120–123	11.9	1.3
4th	3.0–4.5	19.0	2.5	111–119	17.6	1.7
5th (most severe)	5.0–29.0	38.9	4.1	18–110	38.5	2.9

NOTE. The DRS C index $\pm$ SE is .80$\pm$.01, AIC=11,005, and hazard ratio per 1-unit increase in DRS is 1.13. The FIM C index $\pm$ SE is .80$\pm$.01, AIC=11,015, and hazard ratio per 1-unit decrease in FIM is 1.02.
* Computed by dividing total deaths by person-years of exposure and multiplying by 1000.
† Proportional hazards regression model with quintile indicators, adjusted for sex and age.

Discussion

Both the FIM and DRS are useful measures for long-term survival prognosis and the estimation of mortality risk. The DRS appears to capture a wider spectrum of disability severity than the FIM. A DRS score of 0 is associated with lower mortality rates than a FIM score of 126. Conversely, persons with the highest DRS scores tend to have poorer survival than those with the lowest FIM scores. DRS- and FIM-based models ranked survival times equally well (both C indices: .80), and the AIC statistics were quite similar (DRS: 11,005 vs FIM: 11,015).

Our goal was to produce a tool for prognosis that balanced statistical performance with interpretability and simplicity for use in practical settings. We found that the DRS item level of functioning, which speaks to individual care needs, captured nearly as much variation in survival time as the total DRS or FIM scores. Our proposed survival prognosis model contains only 4 levels based on care needs: (1) largely independent, minimal assistance at most; (2) requires mechanical aids or assistance with some activities; (3) requires assistance with all activities, 24-hour home care; and (4) total dependence, requires 24-hour nursing care. These classifications may be readily made in clinic, via phone interview, or through record review. Further, valid classification of an individual into one of these groups requires no particular clinical expertise; thus, a relatively simple prognostic tool based on empirical evidence is provided to anyone involved in long-term care planning for persons with TBI.

Time since injury proved not to have an effect on mortality rates. We found that the SMR remained elevated for 20 years after injury, and the person-year analysis confirmed that this result stood after adjustment for age and severity of disability. These results are consistent with those of Baguley,[12] Ratcliff,[13] and colleagues, who found elevated SMRs for at least 12 and 19 years postinjury, respectively. Once a person's current age and pattern of disability has been taken into account, the age at which they acquired their TBI is not a major factor for survival prognosis. The survival prognosis for a 40-year old with a TBI is the same whether they were injured at age 35 years or at age 25 years.

We found no secular trend in long-term TBI mortality rates. That is, the survival prognosis for an individual who suffers TBI today is about the same as it was for a person with comparable disabilities who suffered TBI 20 years ago. This finding is consistent with results from California during years 1988 to 2006[17] and those from Australia in years 1990 to 2010.[12] Although the Colorado inpatient study[3] suggested a significant improvement in mortality during years 1950 to 1990, this apparently has not continued during the last 2 decades. In contrast with these results, some work from the TBI Model Systems suggested that survival has become worse, although this may have been an artifact of the analysis,[19] which relied on the Cox model as opposed to the more powerful time-dependent person-year methods used in the present study.

The need for careful selection of appropriate statistical methods in the estimation of secular trends is highlighted by contrasts in our own SMR and logistic person-year regression results. Although the overall SMR decreased in recent calendar years, the age- and disability-specific mortality rates did not. Subsequent analysis revealed that this was largely explained by a decrease in the average severity of disability and an increase in the average participant age in more recent calendar years. An investigation of the underlying reasons for this change in the case mix is beyond the scope of this article.

Table 3 Logistic regression person-year analysis of temporal effects

Covariate	Mortality Odds Ratio*	95% CI
Years since injury†	1.0	1.0–1.0
Calendar year 1989–1999 (reference)	1.0	NA
2000–2011	1.0	0.8–1.3

Abbreviation: NA, not applicable.
* Adjusted for sex, age, and total DRS score.
† Linear term.

Study limitations

This study has several limitations. Because the TBI Model Systems includes adults with moderate to severe TBI who are thought to benefit from rehabilitation, persons with very mild or extremely severe disabilities are underrepresented. Persons with concussions, for example, are absent. Given this limitation, we emphasize that the survival prognosis tools presented here are inappropriate for adults with very mild injuries, that is, those who do not have any physical or cognitive disability. Similar comments apply to the extreme disability case, for example vegetative state. The prognoses here are best reserved for adults who have suffered a moderate to severe TBI and who have ongoing long-term disability.

Our practical survival prognosis model was based on 4 relatively broad comparison groups, within which individual survival times varied considerably. As documented in the results, some of this variation may be explained by incorporating more detailed information on functional disabilities, for example through the inclusion of more detailed information from the DRS or FIM. Other potential sources of variation may include noninjury demographic or behavioral factors. Though with regard to race, the survival prognosis for black study participants was not significantly different than white participants after adjustment for the severity of disability.

We purposefully excluded several noninjury risk factors from the prognostic model. Although the TBI Model Systems do collect information on education, employment, alcohol use, and other factors, the sample size used here was not sufficient to allow their inclusion into the model without increased instability of the resulting estimates. Behavioral risk factors undoubtedly have significant and complex interactions with the severity of disability. For example, a history of alcohol abuse would be a major factor among people with mild disability, mainly because they are likely to continue the habit. Conversely, a history of risky behaviors may have a weaker association with survival for persons with very severe disability, simply because such persons may be physically unable to continue to smoke or drink after injury.

Consistent with the tenets of evidence-based practice, we emphasize that, in addition to the estimates derived from this study, the results of other studies together with individual patient characteristics should always be carefully considered when delivering survival prognosis estimates.

Conclusions

This study confirms that severity of disability is one of the most important factors for long-term survival in persons with TBI. Our proposed survival prognosis model, which is based on care needs, has comparable statistical performance to models based on the total DRS and FIM scores and has several practical advantages. The lack of time since injury and secular trend effects provide further support for the use of these results for survival prognosis in contemporary cases of moderate to severe TBI. Survival prognosis estimates based on this study may now be obtained through an online calculator, which may be keyed to an individual's current age, sex, and severity of disability. The calculator is available online (http://www.LifeExpectancy.org/tbims.shtml).

Suppliers

a. SAS Institute Inc, 100 SAS Campus Drive, Cary, NC 27513-2414
b. R Foundation for Statistical Computing. Available at: http://www.r-project.org/.

Keywords

Brain injuries; Mortality; Rehabilitation; Survival

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