

ORIGINAL RESEARCH

Long-Term Survival After Traumatic Brain Injury Part I: External Validity of Prognostic Models



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Abstract

Objectives: To develop prognostic models for long-term survival in adults with traumatic brain injury (TBI) and to assess their external validity in 2 independent populations.

Design: Survival analysis.

Setting: Post-discharge from rehabilitation units and long-term follow-up at regional centers.

Participants: Two cohorts of long-term survivors of TBI (N=12,481): the Traumatic Brain Injury Model Systems (TBIMS) cohort comprised 7365 persons who were admitted to a TBIMS facility and were assessed at ≥ 1 years postinjury, and the California Department of Developmental Services (CDDS) cohort comprised 5116 persons who sustained a TBI and received long-term services from the CDDS.

Interventions: Not applicable.

Main Outcome Measures: Survival/mortality.

Results: Older age, male sex, and severity of disability in walking and feeding were significant predictors of increased long-term mortality rates (all $P < .05$, both databases). The CDDS model predicted 623 deaths for persons in the TBIMS cohort, with an observed-to-expected ratio of .94 (95% confidence interval [CI], 0.87–1.02). The TBIMS model predicted a total of 525 deaths for persons in the CDDS cohort, with an observed-to-expected ratio of 1.08 (95% CI, 0.99–1.17). Regression calibration statistics were satisfactory, and both models ranked survival times well from shortest to longest (TBIMS: C index, .78; 95% CI, .76–.80; CDDS: C index, .80; 95% CI, .78–.82).

Conclusions: Long-term survival prognosis in TBI is related to age, sex, and severity of disability. When compared on the basis of these factors, the survival estimates derived from the TBIMS and CDDS cohorts are found to be similar. The close agreement between model predictions and actual mortality rates confirm the external validity of the prognostic models presented herein.

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Mortality rates of persons who have sustained a traumatic brain injury (TBI) with long-term disabilities are higher than those of the general population.¹⁻¹⁶ Because of this, individual prognosis for survival should be based on the mortality experience of persons with similar injuries and disabilities rather than on standard government tables. For example, Shavelle et al⁷ found that life expectancies of persons with TBI who received services from the

California Department of Developmental Services (CDDS) varied dramatically according to walking and feeding skills.

It is natural to ask whether prognostic estimates derived from a particular cohort apply equally well to persons with TBI from other states or countries where components of the health care system or population demographics may differ. In epidemiology, the ability of a prognostic model to make predictions for new cases outside the derivation cohort is known as external validity.¹⁷

A formal assessment of external validity is rarely reported in the research literature because it requires the collection of data from an independent validation cohort, which is often prohibitively expensive. When such assessments are carried out, the

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results may reveal the accuracy of a model to be lower on the validation cohort than on the derivation cohort. Potential reasons for this include (1) overfitting of the statistical model; (2) measurement errors associated with the interobserver variability of predictors; or (3) omission of important predictive variables.¹⁷ Given this, clinicians and researchers are often skeptical of the applicability of prognostic models. Hence, validation studies are of utmost importance in the translation of research into practical tools.

In this article, we derive models for long-term mortality rates of persons with TBI from 2 independent cohorts and assess the external validity of these models by using a 2-sample cross-validation procedure. We derive the first model from an updated and expanded CDDS cohort that was studied previously by Shavelle.⁷ Its external validity is tested against a validation cohort comprising persons with TBI who received care at the National Institute on Disability and Rehabilitation Research—funded Traumatic Brain Injury Model Systems (TBIMS) centers. Likewise, we derive a separate prognostic model from the TBIMS cohort and compare its predictions to actual outcomes in the CDDS cohort.

Methods

This study was approved by the HCA-HealthONE Institutional Review Board at the TBIMS National Data and Statistical Center, Craig Hospital, Englewood, CO.

Cohorts and comparison groups

The TBIMS and CDDS study cohorts are described in supplemental appendix S1 (available online only at <http://www.archives-pmr.org/>). In brief, the TBIMS cohort included persons who sustained a TBI at the age of ≥ 16 , received comprehensive acute and rehabilitation care at a TBIMS center,¹⁸ and provided follow-up information on functional skills assessed with the FIM instrument¹⁹ ≥ 1 year postinjury. The CDDS cohort comprised persons with TBI who received services from the CDDS and provided long-term follow-up information on functional skills assessed with the Client Development Evaluation Report (CDER).²⁰⁻²³ The vital status of TBIMS and CDDS cohorts was ascertained through the Social Security Death Index (SSDI) and the California Department of Public Health, respectively.

For simplicity, and to allow comparison with previous work, we chose to work with the 4 comparison groups considered in the 2007 study of Shavelle⁷: (1) does not walk, fed by others (CDER: walking = 1, feeding = 1; FIM: walking ≤ 5 , feeding ≤ 3); (2) does not walk, self-feeds (CDER: walking = 1, feeding ≥ 2 ; FIM: walking ≤ 5 , feeding ≥ 4); (3) some walking with a handheld device or unsteadily alone (CDER: walking = 2 or 3; FIM: walking = 6); and (4) walks well alone (CDER: walking = 4; FIM: walking = 7).

List of abbreviations:

CDDS	California Department of Developmental Services
CDER	Client Development Evaluation Report
CI	confidence interval
O/E	observed-to-expected
SSDI	Social Security Death Index
TBI	traumatic brain injury
TBIMS	Traumatic Brain Injury Model Systems

Survival analysis and model validation

We computed empirical mortality rates of various subgroups by dividing the count of observed deaths by the total number of person-years of follow-up. We used multiplicative hazard regression²⁴ in each cohort to model mortality rates as a function of age, sex, and the 4 walking-feeding groups described above.

The regression model fitted to the CDDS cohort was used to predict mortality in the TBIMS cohort. Likewise, the TBIMS model was used to predict mortality in the CDDS cohort. That is, the TBIMS cohort served as the validation cohort for the CDDS model, and vice versa. We did not attempt to predict exactly when any particular individual would die. Instead, we computed a series of age-specific mortality rates and survival probabilities (ie, survival curves) for each individual. External validity was then assessed with measures of calibration and discrimination.^{17,25}

Calibration of both models was assessed by comparing the number of deaths expected according to each model with the observed number in their respective validation cohorts. The expected numbers of deaths according to the models were computed by multiplying the mortality rates (which have units of deaths per person-year) by the number of person-years of follow-up. We calculated the observed-to-expected (O/E) ratios for various subgroups and computed 95% confidence intervals (CIs) based on the assumption that observed death counts followed a Poisson distribution. We also assessed calibration graphically by plotting the number of observed deaths versus the number of expected deaths by model-based risk deciles. This calibration plot allowed a visual assessment of whether the model systematically over- or underestimated mortality of low-, medium-, or high-risk groups.

We formally tested whether the prediction models required “recalibration in the large” or “shrinkage” by using regression methods. The recalibration in the large uses the original model predictions as a regression offset and tests whether a recalibration intercept indicates a significant over- or underestimation of mortality across the validation cohort as a whole. A well-calibrated model should have a recalibration intercept equal to 0. The recalibration through shrinkage uses the original model predictions as a covariate in a regression model, whose coefficient is the so-called recalibration slope. A well-calibrated model should have a recalibration slope coefficient equal to 1, which means that no shrinkage or expansion is required to adequately model the variability in the mortality of low- and high-risk groups.

Discrimination, that is, the ability of the model to rank survival times from shortest to longest, was assessed with the C index.

Data were analyzed with SAS version 9.2^a and R version 3.0^b software.

Results

Descriptions of the cohorts

The TBIMS cohort comprised 7365 persons (5400 men, 73% men), of whom 587 died over the course of 33,481 (collective) person-years of follow-up. The CDDS cohort included 5116 persons (3405 men, 67% men), of whom 568 died over the course of 54,306 person-years of follow-up. Thus, the empirical mortality rates were 17.5 (95% CI, 16.1–19.0) and 10.5 (95% CI, 9.6–11.4) deaths per 1000 person-years in TBIMS and CDDS cohorts, respectively.

Differences in the empirical mortality rates were partially explained by differences in the distributions of age and severity of

Table 1 Cohort characteristics

Variable	TBIMS (n=7365)	CDDS (n=5116)
No. of deaths	587	568
Sex: male	73	67
Age at first study evaluation (y)	40.1±17.9	24.7±13.7
Walking		
Walks well	62	65
Some walking	28	17
Does not walk	10	18
Feeding		
Self-feed	97	87
Fed by others	3	13
Calendar year at evaluation	2003 (±4.3y)	1997 (±6.9y)

NOTE. Values are presented as mean ± SD or as percentage. The distributions of continuous and categorical variables were compared using *t* tests and χ^2 tests, respectively. All differences were statistically significant at $P < .05$.

disability (table 1). For example, the TBIMS cohort was significantly older than the CDDS cohort (mean age, 40.1y vs 24.7y; $P < .0001$). However, the effect of this age difference on mortality was attenuated by the fact that the disabilities of persons in the TBIMS cohort were, on average, less severe. Only 3% of persons in the TBIMS cohort were fed by others compared with 13% in the CDDS cohort ($P < .05$). Persons in the CDDS cohort were nearly twice as likely to be nonambulatory (18% vs 10%; $P < .05$).

Differences in the distribution of race largely reflect known patterns in California and the United States; namely, California has a higher proportion of Hispanic individuals. Differences in the average calendar year of evaluation (TBIMS: 2003 vs CDDS: 1997; $P < .05$) reflect the fact that TBIMS started collecting data only in 1988, considerably later than did the CDDS, which began large-scale data collection in 1980.

Mortality rates

Mortality rates increased with advancing age and severity of disability, and men had higher mortality rates than did women. The age- and disability-specific empirical mortality rates were similar in CDDS and TBIMS cohorts. For example, the mortality rates of persons aged 17 to 39 years who walked well were 3.7 (95% CI, 2.9–4.1) and 4.1 (95% CI, 3.1–5.4) deaths per 1000 person-years in CDDS and TBIMS cohorts, respectively. The 95% CIs of the age- and disability-specific empirical mortality rates in CDDS and TBIMS cohorts overlapped for all groups considered.

The Poisson regression models for mortality rates derived from the CDDS and TBIMS cohorts are shown in table 2. As expected, the models indicated that persons with more severe disabilities had higher mortality rates after adjustment for age and sex (all $P < .05$). In both TBIMS and CDDS cohorts, we found that mortality rates of ambulatory men were higher than those of ambulatory women (CDDS: hazard ratio, 1.5; 95% CI, 1.2–1.9; TBIMS: hazard ratio, 1.6; 95% CI, 1.2–1.9). In the TBIMS cohort, we found that the mortality rates of the ambulatory groups and those who did not walk but did self-feed increased at 6% (95% CI, 5.4–6.4) for each additional year of age. For those who were fed by others, mortality rates increased more slowly at 5% (95% CI, 3.6–6.2) per year of age. In the CDDS cohort, we found that the mortality rates of self-feeders increased at 7% (95% CI, 6.1–7.3) for each additional

year of age. For those who were fed by others, mortality rates increased more slowly (1% per year) up to age 50 years and then accelerated to 7% per year after age 50 years. White race did not confer a significant survival advantage in either database (CDDS: $P = .98$; TBIMS: $P = .96$), and we therefore chose not to include this factor in our prognostic models.

External validity

For persons in the TBIMS cohort, the CDDS statistical model predicted 623 (expected) deaths with an O/E ratio of .94 (95% CI, 0.87–1.02). Visual inspection of the plot shown in figure 1 indicated good calibration across the mortality risk spectrum, though there was an apparent underestimation of mortality for the lowest risk decile and apparent overestimation of mortality for the highest risk decile. The recalibration regression test of “calibration in the large” was consistent with the overall O/E ratio (recalibration intercept coefficient, $-.06$; $P = .15$). The recalibration slope coefficient was 1.00 (95% CI, 0.98–1.03), which indicates that the estimated covariate effects adequately captured variation in mortality risks. The CDDS model also performed well with regard to ranking the TBIMS survival times from shortest to longest, achieving a C index of .80 (95% CI, .78–.82).

Predictions from the CDDS model proved accurate across all disability-specific subgroups in the TBIMS cohort (table 3). For the “walks well” group, the CDDS model predicted 257 deaths compared with the 237 actually observed (O/E ratio, .92; 95% CI, 0.81–1.05). In the “some walking” and “fed by others” groups, the predicted number of deaths, 214 and 57, were even closer to the 213 and 56 actually observed. With regard to age, the CDDS model predicted 81 TBIMS deaths in the age range 17 to 39 years, which was identical to the 81 actually observed. The model underestimated mortality in the age range 40 to 59 years (O/E ratio, 1.14; 95% CI, 0.99–1.31) and overestimated mortality in the age range 60 to 79 years (O/E ratio, .86; 95% CI, .74–.99) and ≥ 80 years (O/E ratio, .80; 95% CI, .67–.96). These results are consistent with the calibration plot shown in figure 1, as the oldest individuals in the TBIMS cohort tend to be those with the highest mortality risks.

For the CDDS cohort, the TBIMS model predicted 525 deaths, which was somewhat lower than the 568 deaths actually observed (O/E ratio, 1.08; 95% CI, 0.99–1.17). The calibration plot shown in figure 2 indicates good accuracy across the risk spectrum. The only deviation significant at a 5% level was an underestimation of mortality in the 9th risk decile, though predicted values were quite close for the 10th decile with the highest risk. The recalibration intercept coefficient of .08 ($P = .06$) for “calibration in the large” was again consistent with the overall O/E ratio. The recalibration slope coefficient was .98 (95% CI, 0.97–1.00), and the C index was .78 (95% CI, .76–.80).

The TBIMS model predicted 228 of 231 observed deaths in the CDDS “walks well” group and 60 of 60 in the “does not walk, self-feeds” group (see table 3). The 114 predicted deaths for the “some walking” group was not statistically different from the 102 actually observed deaths (O/E ratio, .89; 95% CI, 0.73–1.09). However, the TBIMS model significantly underestimated mortality in the “does not walk, fed by others” group, predicting only 123 of 175 actually observed deaths (O/E ratio, 1.43; 95% CI, 1.22–1.66). With regard to age, the TBIMS model significantly underestimated mortality of CDDS children and teenagers aged 10 to 16 years (O/E ratio, 1.75; 95% CI, 1.28–1.33), though the

Table 2 Regression models for long-term mortality rates*

Covariate	TBIMS				CDDS			
	Hazard Ratio	95% CI		P	Hazard Ratio	95% CI		P
Male × Ambulatory	1.55	1.24	1.93	.0001	1.50	1.19	1.91	.0008
Walks well	1.00	(reference group)			1.00	(reference group)		
Some walking	1.74	1.44	2.10	.0001	1.52	1.20	1.92	.0004
Does not walk, self-feeds	3.07	2.25	4.18	.0001	2.95	2.12	4.11	.0001
Does not walk, fed by others	12.32	4.97	30.53	.0001	75.40	43.51	130.67	.0001
Age × (Ambulatory or self-feeds)	1.06	1.05	1.06	.0001	1.07	1.06	1.07	.0001
Age × Fed by others	1.05	1.04	1.06	.0001	1.01	0.99	1.02	.3218
I (Age >50y) × (Age 50y) × Fed by others	NA	NA	NA	NA	1.06	1.01	1.12	.0312

Abbreviation: NA, not applicable.

* Poisson regression using the death indicator as the outcome and the natural logarithm of person-years of exposure as an offset on the right-hand side of the regression equation. The modeling exercise suggested that the additional term for persons who were fed by others and were older than 50y was not required in the TBIMS cohort.

predictions were not significantly different from the observed numbers for persons aged ≥17 years.

Discussion

This is the first study to examine the external validity of statistical models for long-term survival prognosis in persons with TBI. Although the population profiles for the CDDS (younger with more severe disabilities) and TBIMS (older with milder disabilities) cohorts were different, the key predictors of increased mortality—older age, male sex, and severity of disability in walking and feeding—and their effects were similar in both cohorts. We found the empirical mortality rates in the CDDS cohort to be similar to those in the TBIMS cohort, and the hazard ratios associated with age, sex, and disability in our regression analyses were also similar in both cohorts.

One difference in the CDDS and TBIMS mortality models was the gradient of the mortality-age curve for persons who did not

walk and were fed by others. The CDDS model indicated a relatively slow increase up to age 50 years, which then accelerated to a more typical aging effect thereafter. In contrast, the TBIMS model indicated a 5% increase per year across the age span for a parsimonious fit. The TBIMS model, which in comparison to the CDDS model contains less data on young persons with severe disabilities, may have lacked the statistical power to detect the pattern seen in the CDDS model. The CDDS model may provide better mortality estimates than the TBIMS model for young persons with severe disabilities.

The validation study demonstrated that the models for mortality rates derived separately from the CDDS and TBIMS cohorts achieved excellent predictive performance, as assessed with O/E ratios, calibration plots, and the C index for discrimination. The overall numbers of observed and expected deaths (in each cohort and model) did not differ significantly. It would be unreasonable to expect the models to have perfect external validity for every subgroup considered. Reasons include simple statistical variability, differences in patient characteristics that were not included in the models, and differences in the way walking and feeding skills were assessed (ie, FIM in the TBIMS cohort vs CDER in the CDDS cohort). Nonetheless, nearly all of the nearly all of the 95% CIs of O/E ratios for the subgroups listed in table 3 included the value 1, which attests to the external validity of the prognostic models for mortality rates derived from both CDDS and TBIMS cohorts.

A significant over- or underestimation of mortality was apparent in some subgroups of the validation cohorts. These tended to be groups for which the respective derivation cohorts had relatively sparse data. For example, the CDDS model overestimated mortality in persons in the TBIMS cohort aged ≥60 years by 16% to 20% (P<.05). Because the CDDS cohort comprises mainly teenagers and younger adults, estimates of mortality derived from the CDDS cohort at older ages are prone to lower precision than are estimates of mortality at younger ages. Conversely, the TBIMS model underestimated mortality of CDDS children and teenagers aged 10 to 16 years by 75% (P<.05). However, this comparison may be unfair, because the TBIMS cohort did not include any persons in this age range. In general, the mortality rates derived from the TBIMS cohort should not be applied to children.

The TBIMS model also underestimated mortality by 43% (P<.05) in persons who did not walk and were fed by others i.e.,

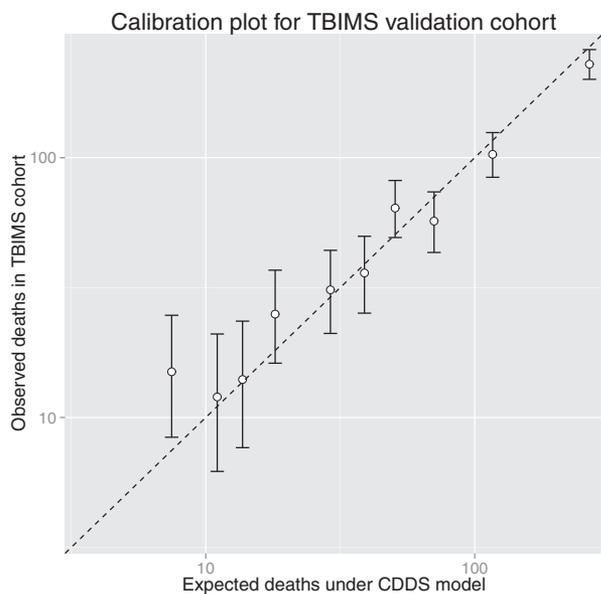


Fig 1 Calibration of the CDDS model to the TBIMS cohort (recalibration intercept coefficient, .06; P=.15; recalibration slope coefficient, 1.00; 95% CI, 0.98–1.03).

Table 3 Validation of models using age, sex, and walking and feeding skills for long-term mortality rates

Variable	TBIMS				CDDS			
	Observed	Expected	O/E Ratio	95% CI	Observed	Expected	O/E Ratio	95% CI
Overall	587	623	0.94	0.87 1.02	568	525	1.08	0.99 1.17
Male	444	452	0.98	0.89 1.08	388	360	1.08	0.97 1.19
Female	143	171	0.84	0.70 0.98	180	165	1.09	0.93 1.26
Walks well	237	257	0.92	0.81 1.05	231	228	1.01	0.88 1.15
Some walking	213	214	0.99	0.86 1.14	102	114	0.89	0.73 1.09
Does not walk, self-feeds	81	95	0.85	0.68 1.06	60	60	1.00	0.77 1.29
Does not walk, fed by others	56	57	0.98	0.74 1.27	175	123	1.43	1.22 1.66
Age (y)								
10–16	NA*	NA*	NA*	NA* NA*	46	26	1.75	1.28 2.33
17–39	81	81	1.00	0.79 1.24	227	203	1.12	0.98 1.27
40–59	201	176	1.14	0.99 1.31	175	189	0.92	0.79 1.07
60–79	179	209	0.86	0.74 0.99	103	94	1.09	0.89 1.32
>80	126	157	0.80	0.67 0.96	17	12	1.44	0.84 2.30

* The TBIMS cohort did not have any individuals younger than 17y.

the group with the most severe disabilities. The reasons for this are not entirely clear, but may be related to differences between the inclusion criteria of CDDS and TBIMS cohorts. In particular, the TBIMS cohort includes only those persons with moderate to severe TBI who were admitted to inpatient rehabilitation. Thus, persons with extremely severe disabilities, for example, those in a vegetative state or others deemed unlikely to benefit from rehabilitation, may not have been included. In contrast, the CDDS cohort includes (by law) all such individuals regardless of rehabilitation considerations and may therefore include a proportionately higher number of the most severely disabled individuals. For this reason, the estimates derived from the CDDS cohort may be preferable for persons with extremely severe disabilities.

Whether the CDDS and TBIMS models presented here provide accurate prognosis for persons with TBI outside the United States

is less clear. In persons with other neurological conditions, such as spinal cord injury²⁶⁻²⁸ and cerebral palsy,²⁹⁻³¹ registries from the United Kingdom, Australia, and other countries have reported long-term survival probabilities that are similar to those from the National Institute on Disability and Rehabilitation Research–funded Spinal Cord Injury Model Systems and the CDDS, respectively. To our knowledge, there are no large TBI databases from other countries that contain detailed longitudinal information on walking and feeding skills. Perhaps the best opportunity to examine the external validity of survival prognosis models outside of the United States is the Australian database underlying the work of Baguley et al,¹² which contains information on the total FIM score at discharge from inpatient rehabilitation.

Study limitations

One important limitation of this study is the coarseness of the walking-feeding groupings used in the prognostic models. As noted previously, we used these groupings for 2 reasons. The first was to facilitate comparisons with earlier work that used the same groupings,⁷ and the second had to do with practical considerations related to the validation procedure. The simplicity of the models here should not be interpreted as a limitation of the CDDS or TBIMS databases. Both the CDER (used to collect data in the CDDS) and the FIM instrument (used to describe functional independence in the TBIMS) give detailed clinical information on many functional skills such as dressing, bathing, toileting, and stair climbing, all of which are potentially useful predictors of long-term mortality. However, the skill levels for each activity as described in the CDER do not share a 1-to-1 correspondence with those described in the FIM instrument. Hence, the inclusion of more variables with imprecise matching of skill level criteria would have increased the uncertainty in the validation results. A second limitation is the absence of noninjury factors in our analysis. Unfortunately, there were no data on smoking in either database and the information on alcohol, illicit drugs, and other potentially relevant noninjury factors was limited. Finally, we note that the results obtained herein, which are based on the analysis of persons served at the TBIMS or CDDS centers, may not apply to persons with mild TBI who do not require inpatient rehabilitation or long-term services.

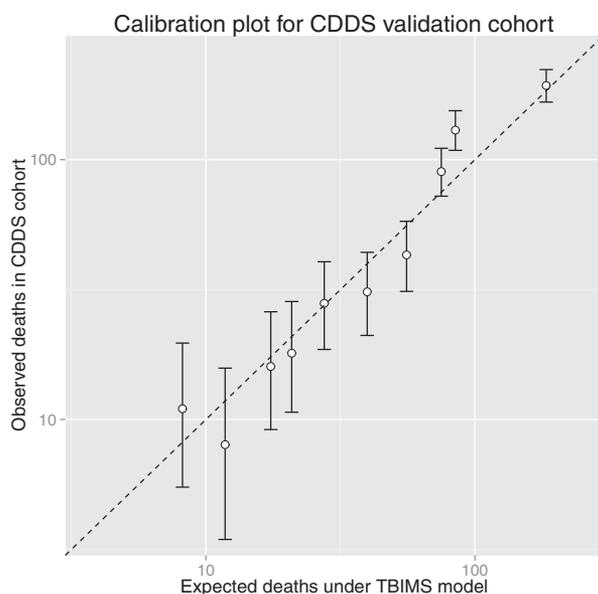


Fig 2 Calibration of the TBIMS model to the CDDS cohort (recalibration intercept coefficient, .08; $P = .06$; recalibration slope coefficient, .98; 95% CI 0.97–1.00).

Conclusions

Older age, male sex, and severity of functional disability in walking and feeding are simple but powerful predictors of increased long-term mortality in persons with TBI. Despite underlying differences in the CDDS and TBIMS, statistical models for mortality rates derived from each cohort accurately predicted survival in the other. The external validity of these models provides strong support for their use in practical prognostic work.

Suppliers

- a. SAS Institute Inc.
- b. R Foundation for Statistical Computing.

Keywords

Brain injuries; Mortality; Survival; Prognosis; Rehabilitation; Validation studies

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Supplemental Appendix S1 Details on TBI Cohorts

TBIMS cohort

The TBIMS cohort comprised persons with TBI who were admitted to 1 of 20 TBIMS hospitals with a medically documented loss of consciousness or posttraumatic amnesia due to brain trauma or objective neurological findings attributed to TBI on physical examination or mental status examination. In general, persons included in the national database must (1) meet at least 1 of the following criteria for moderate to severe TBI: posttraumatic amnesia for >24 hours, trauma-related intracranial neuroimaging abnormalities, loss of consciousness for >30 minutes, a Glasgow Coma Scale score of <13 in the emergency department (unless due to intubation, sedation, or intoxication); (2) have age \geq 16 years at the time of injury; (3) present to the TBIMS acute care hospital within 72 hours of injury; (4) receive both acute hospital care and comprehensive brain injury rehabilitation within the designated TBIMS hospital; and (5) provide informed consent to participate or have a proxy provide consent. Functional status of each participant is assessed at rehabilitation admission and discharge and at long-term follow-up evaluations performed at 1, 2, 5, 10, 15, and 20 years postinjury. Details on data collection and follow-up protocols are fully documented in previous work.¹ Our study cohort included persons in the TBIMS cohort injured between 1988 and 2010 who provided a complete follow-up assessment at the 1-year postinjury evaluation or later.

Functional walking and feeding skills were recorded using the FIM instrument.² Each domain is scored on a 7-point scale, where 1 indicates complete dependence and 7 indicates complete independence. For walking, a score of 7 means that the patient safely walks a minimum of 150 ft without assistive devices. A score of 6 indicates that patient walks a minimum of 150 ft but uses a supportive device such as a cane, crutch, or walker; takes more than a reasonable amount of time to complete the activity; or has safety considerations. Scores of \leq 5 are assigned to persons who walk only short distances under supervision, with cueing or coaxing, or with the assistance of another person. FIM feeding scores of \geq 4 indicate that the person performs \geq 75% of typical feeding tasks, whereas scores of \leq 3 indicate nutrition largely administered by another person orally or via a feeding tube.

The vital status of each participant was ascertained using the SSDI just before follow-up interviews. SSDI matching has been shown to have a sensitivity of 89% and a specificity of 100% in the TBIMS population.³ The vital status of persons without an SSDI match 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.

CDDS cohort

The CDDS cohort comprised persons with TBI who received services from 1 of 20 CDDS regional centers. To qualify for

services, that is, medical care, physical and occupational therapy, housing, and so on, persons must have a medically documented developmental disability or an acquired neurological injury that has led to substantial disability before age 18 years. Thus, the CDDS cohort comprises mainly persons who sustained a TBI before age 18 years and others with preexisting developmental disability who sustained a TBI as adults. Persons served by the CDDS are assessed annually with the CDER,⁴ a 200-item survey of medical diagnoses and functional, behavioral, and cognitive skills. For each person, a team headed by a physician makes medical diagnoses, including TBI, which are coded according to the *International Classification of Disease, Ninth Revision (ICD-9)* and *International Statistical Classification of Disease, 10th Revision (ICD-10)*.⁵ We included persons with codes for skull fracture (ICD-9 codes 800–804, 905.0; ICD-10 code S02), intracranial injury without skull fracture (ICD-9 codes 850–854, 907.0; ICD-10 code S07), postconcussion syndrome (ICD-9 code 310.2; ICD-10 code F07.81), and unspecified head injury (ICD-9 code 959.01; ICD-10 codes S09.8, S09.9). Notably, sensitivity analyses that excluded persons with postconcussion syndrome and unspecified head injury did not change results substantially. We also included persons with cognitive disabilities secondary to a vehicle accident. Those who had a concomitant diagnosis of any of several degenerative or congenital conditions were excluded from the analysis. The final study cohort comprised persons who met these criteria and were evaluated at age \geq 10 years over the study period from 1988 to 2010.

Functional walking and feeding assessments were recorded on the CDER by professionals familiar with that aspect of the client's development. The functional skill levels recorded on the CDER describe voluntary actions that are performed on a consistent basis in typical settings. They do not represent the best level that has been or may be achieved in specialized settings. The walking scale had 4 levels: (1) does not walk; (2) walks with support (eg, a handheld device); (3) walks unsteadily alone 10 ft; and (4) walks well alone 20 ft, balances well. The feeding scale had 6 levels: (1) does not feed self; (2) attempts to finger feed, but needs assistance; (3) finger feeds without assistance; (4) feeds self using spoon, with spillage; (5) feeds self using fork and spoon, with spillage; and (6) uses eating utensils with no spillage. The demographic and functional skill data recorded on the CDER were consistently coded, with <1% missing values. Missing data were imputed using the last observation carried forward. The assessments of these skills that were recorded on the CDER have been independently validated and have interrater reliabilities exceeding .85.^{6,7}

The vital status was determined using electronic death records from the California Department of Public Health. To minimize potential biases associated with out-of-state migration, persons who were not matched to a death record within 3 years of their last CDER were considered lost to follow-up at the 3-year mark. Individual survival times were censored at the date of loss to follow-up or the study end date, December 31, 2010, whichever came first. Both sensitivity and specificity of the matching of death records from the California Department of Public Health exceeded 98%.

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