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ORIGINAL RESEARCH

Long-Term Survival After Traumatic Brain Injury Part II: Life Expectancy

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Abstract

Objectives: To compute the life expectancy of persons with traumatic brain injury (TBI) based on validated prognostic models from 2 cohorts, to compare mortality and life expectancy of persons with TBI with those of the U.S. general population, and to investigate trends toward improved survival over the last 2 decades.

Design: Survival analysis.

Setting: Postdischarge 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 with moderate to severe TBI 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: Life expectancy.

Results: The estimates of age-, sex-, and disability-specific life expectancy of persons with TBI derived from the CDDS and TBIMS were similar. The estimates of age- and sex-specific life expectancy were lower than those of the U.S. general population. Mortality rates of persons with TBI were higher than those of the U.S. general population. Mortality rates did not improve and the standardized mortality ratio increased over the study period from 1988 to 2010.

Conclusions: Life expectancy of persons with TBI is lower than that of the general population and depends on age, sex, and severity of disability. When compared, the survival outcomes in the TBIMS and CDDS cohorts are remarkably similar. Because there have been no marked trends in the last 20 years, the life expectancies presented in this article may remain valid in the future.

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Life expectancy is defined as the mean survival time in a group of similar people. It is normally derived from an actuarial life table that is based on a set of age-specific mortality rates or survival probabilities. Hence, life expectancy is often taken to be a summary measure of population health. For individuals, particularly those with disabilities who require lifelong care, life expectancy is a convenient summary of age-specific survival probabilities and plays a central role in medical and financial planning.

Persons with moderate to severe traumatic brain injury (TBI) do not live as long, on average, as uninjured persons in the general population.[1-16] Through examination of the National Institute on Disability and Rehabilitation Research–funded Traumatic Brain Injury Model Systems (TBIMS) national database, Harrison-Felix et al[3] found that the life expectancy of persons with moderate to severe TBI was reduced by 3 to 11 years, depending on age, sex, and race. This range increases dramatically when severity of long-term disabilities are also considered. For example, in a study of persons with TBI who were clients of the California Department

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of Developmental Services (CDDS), Shavelle et al[7] found that the life expectancy of 10-year-old girls with TBI who did not walk and were fed by others was 43 years lower than that of the age- and sex-matched general population. The same study indicated that the reduction in life expectancy of 50-year-old men with TBI who walked well was only 4 years.

In this article, we work with an updated and extended version of the CDDS database studied by Shavelle[7] together with the TBIMS national database to derive new estimates of life expectancy according to age, sex, and disabilities in walking and feeding. We compare mortality rates of persons with TBI with those of age- and sex-matched persons in the U.S. general population and examine whether there have been trends toward improved survival over the last 20 years.

Methods

This study was approved by the Hospital Corporation of America-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, who received comprehensive acute and rehabilitation care at a TBIMS center,[17] and who provided follow-up information on functional skills. The CDDS cohort included persons with TBI who received services from the CDDS. In each cohort, persons were classified into 4 comparison groups on the basis of their walking and feeding skills: (1) does not walk, fed by others; (2) does not walk, self-feeds; (3) some walking with a handheld device or unsteadily alone; and (4) walks well alone. These skills were assessed with the FIM instrument[18] in the TBIMS cohort and with the Client Development Evaluation Report (CDER)[19-22] in the CDDS cohort. The precise levels for each measure were given in our companion article.[23]

Statistical analysis

To estimate life expectancy, we constructed standard actuarial life tables that used age-, sex-, and disability-specific mortality rates as inputs. The mortality rates were taken to be the maximum of (1) the Poisson regression estimates from our companion article[23] and (2) the age- and sex-specific mortality rates of the U.S. general population. That is, we assumed that the mortality rates of the TBI cohorts would not be lower than those of the general population.

We then compared mortality rates of persons with TBI with those of the age-, sex-, and calendar year–matched U.S. general population by using the standardized mortality ratio (SMR). The SMR is calculated as the ratio of the observed number of deaths in a particular group to the expected number of deaths if the group had experienced the mortality rates of the general population. We used the mortality rates of the U.S. general population from the Human Mortality Database.[24]

To examine secular trends in mortality rates, we refit the Poisson regression models from our companion article to test whether mortality rates changed over the study period from 1988 to 2010. A similar extended Poisson regression analysis was used to test for trends in the SMR. In the this SMR regression analysis the natural log of the expected number of deaths in the U.S. general population was used as an offset (ie, a covariate whose coefficient was set to 1) on the right-hand side of the regression equation.[25]

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

List of abbreviations:

CDDS	**California Department of Developmental Services**
CDER	**Client Development Evaluation Report**
CI	**confidence interval**
SCI	**spinal cord injury**
SMR	**standardized mortality ratio**
SSDI	**Social Security Death Index**
TBI	**traumatic brain injury**
TBIMS	**Traumatic Brain Injury Model Systems**

Results

Life expectancy was closely related to the severity of disability as characterized by walking and feeding skills (table 1). Persons with the most severe disabilities had the shortest life expectancy, whereas those most mildly affected had the longest life expectancy. Ambulatory women lived longer, on average, than did ambulatory men. Among persons who did not walk, those who could feed themselves lived longer, on average, than those who could not. There were no significant sex differences among nonambulatory persons.

The life expectancy estimates derived from the CDDS and TBIMS were remarkably similar (see table 1). For example, the life expectancy of 20-year-olds who did not walk and were fed by others was estimated to be 24 and 25 additional years (ie, up to ages 44 or 45y) from CDDS and TBIMS, respectively. On average, 20-year-old men with TBI who walked well lived 9 to 10 years less than those in the general population. For 20-year-old women who walked well, the reduction in life expectancy was 7 to 8 years. Many of the pairwise comparisons of the CDDS and TBIMS life expectancies were identical when rounded to the nearest year. The largest differences were observed for middle-aged adults with the most severe disabilities. For example, the TBIMS life expectancies of 40- to 50-year-olds who did not walk and were fed by others were about 3 years lower than the CDDS life expectancies. The SEs of life expectancy estimates were typically 1 to 2 years, though they were somewhat larger for persons with more severe disabilities.

As in the general population, older persons with TBI had shorter life expectancies than did younger persons. For persons with TBI aged ≤60 years, life expectancy (even of persons who walked well) was lower than the age- and sex-specific life expectancy of persons in the U.S. general population. At the age of ≥70, however, the mortality rates of persons with TBI who walked well were not different from those of typical men and women in the U.S. general population. That is, a person aged ≥70 years who has a TBI and walks well will have an essentially normal life expectancy. Those with more severe disabilities had a shorter life expectancy even at advanced ages.

Our analyses of SMRs (table 2) complement the above-mentioned comparisons of TBI life expectancies with those of men and women in the general population. The overall SMRs for the TBIMS and CDDS cohorts were 2.4 (95% confidence interval [CI], 2.2–2.6) and 3.9 (95% CI, 3.6–4.2), respectively. The latter was higher because the CDDS cohort comprised younger persons with more severe disabilities. When the 2 cohorts were matched for age and severity of disability, the SMRs were similar. In persons aged 17 to 39 years who walked well, for example, the SMRs for CDDS and TBIMS cohorts were 2.8 (95% CI, 2.2–3.5) and 3.1 (95% CI, 2.3–4.0), respectively. For nonambulatory adults aged 40 to 59 years who did not feed

Table 1 Life expectancy: Additional years (SE) for persons with TBI

Sex/Age (y)	CDDS Does Not Walk, Fed by Others	CDDS Does Not Walk, Self-Feeds	CDDS Some Walking	CDDS Walks Well	TBIMS Does Not Walk, Fed by Others	TBIMS Does Not Walk, Self-Feeds	TBIMS Some Walking	TBIMS Walks Well	General Population
Female									
10	26 (1.4)	47 (1.8)	57 (1.9)	62 (1.5)	ND	ND	ND	ND	71.2
20	24 (1.6)	38 (1.7)	47 (1.8)	53 (1.4)	25 (2.5)	38 (1.6)	47 (1.7)	54 (1.7)	61.4
30	21 (1.8)	30 (1.5)	38 (1.7)	44 (1.4)	19 (1.9)	30 (1.4)	38 (1.6)	45 (1.7)	51.6
40	17 (1.9)	23 (1.3)	30 (1.6)	35 (1.3)	14 (1.4)	23 (1.2)	30 (1.4)	37 (1.6)	42.0
50	13 (2.1)	16 (1.1)	23 (1.4)	27 (1.2)	10 (1.0)	17 (1.0)	23 (1.3)	29 (1.5)	32.8
60	8 (2.5)	11 (0.9)	16 (1.2)	20 (1.0)	7 (0.8)	12 (0.8)	17 (1.1)	22 (1.3)	24.1
Male									
10	26 (1.4)	47 (1.8)	51 (1.5)	57 (1.1)	ND	ND	ND	ND	66.3
20	24 (1.6)	38 (1.7)	42 (1.5)	47 (1.1)	25 (2.5)	38 (1.6)	40 (1.1)	48 (1.1)	56.6
30	21 (1.8)	30 (1.5)	33 (1.4)	39 (1.1)	19 (1.9)	30 (1.4)	32 (0.9)	40 (1.0)	47.4
40	17 (1.9)	23 (1.3)	25 (1.3)	30 (1.0)	14 (1.4)	23 (1.2)	25 (0.8)	32 (0.9)	38.1
50	13 (2.0)	16 (1.1)	19 (1.2)	23 (1.0)	10 (1.0)	17 (1.0)	18 (0.7)	24 (0.9)	29.2
60	8 (2.4)	11 (0.9)	13 (1.0)	16 (0.9)	7 (0.8)	12 (0.8)	13 (0.6)	18 (0.8)	21.1

NOTE. The TBIMS does not contain data for persons under age 17.
Abbreviation: ND, no data.

themselves, the SMRs for CDDS and TBIMS cohorts were 14.6 (95% CI, 9.4–21.5) and 17.4 (95% CI, 10.5–27.2). In persons aged ≥80 years who walked well, the SMRs for both cohorts (CDDS: SMR, 1.3; 95% CI, 0.5–2.8; and TBIMS: SMR, 0.7; 95% CI, 0.4–1.1) indicated that the mortality rates of persons with TBI were not significantly different from those of the general population.

With regard to trends over time, we found that after adjustment for sex, age, and severity of disability in walking and feeding, there was no significant improvement in mortality from 1988 to 2010. The hazard ratios associated with the current calendar year were 1.005 (95% CI, 0.991–1.019) in the CDDS cohort and 1.033 (95% CI, 1.009–1.057) in the TBIMS cohort. Because mortality rates of the general population decreased, the SMR actually increased year over year by 2.2% (95% CI, 0.8–3.7) in the CDDS cohort and by 4.9% (95% CI, 2.5–7.3) in the TBIMS cohort.

Discussion

The life expectancy of persons with TBI depends on age, sex, and severity of disability. Walking and feeding skills are powerful predictors that are easy to assess and allow one to reliably distinguish persons with very mild disabilities from those with extremely severe disabilities. Accordingly, the life expectancy of persons with TBI varies considerably, from <40% of the normal life expectancy for those who do not walk and are fed completely by others to >85% of the normal life expectancy for those who walk well alone.

When compared on the basis of age, sex, and functional disability, the survival outcomes in the CDDS and TBIMS cohorts were remarkably similar. In many cases, the life expectancy estimates (rounded to the nearest year) were equivalent. From a technical perspective, this naturally follows from the excellent cross-validated calibration and discrimination statistics of the underlying models.[23] Apparently, the known differences in demographic characteristics of patients from the CDDS and TBIMS cohorts (due to different geographies and case inclusion criteria) have very little, if any, effect on life expectancy after age, sex, and severity of disability are taken into account. From a clinical perspective, one may wonder whether the quality of care provided in each system may have affected the results. The fact that the survival outcomes were similar indicates that either (1) the quality

Table 2 Standardized mortality ratios

Age (y)	Statistic	CDDS Does Not Walk, Fed by Others	CDDS Does Not Walk, Self-Feeds	CDDS Some Walking	CDDS Walks Well	TBIMS Does Not Walk, Fed by Others	TBIMS Does Not Walk, Self-Feeds	TBIMS Some Walking	TBIMS Walks Well
10–16	SMR	97.3	6.3	2.6	3.1	ND	ND	ND	ND
	95% CI	69.5–132.5	0.2–35.0	0.1–14.4	0.8–8.0	ND	ND	ND	ND
17–39	SMR	26.7	6.8	3.1	2.8	9.5	4.8	3.8	3.1
	95% CI	21.8–32.3	4.1–10.4	2.0–4.6	2.2–3.5	3.1–22.3	1.6–11.3	2.3–6.0	2.3–4.0
40–59	SMR	14.6	5.3	4.3	2.3	17.4	4.2	4.5	2.9
	95% CI	9.4–21.5	3.4–8.0	3.1–5.9	1.8–2.8	10.5–27.2	2.3–7.0	3.5–5.7	2.4–3.6
60–79	SMR	5.3	3.4	2.8	2.0	7.6	3.4	2.7	1.4
	95% CI	1.7–12.4	1.8–5.8	1.8–4.0	1.5–2.5	4.6–11.7	2.3–5.0	2.1–3.4	1.0–1.7
≥80	SMR	ND	2.6	2.6	1.3	2.8	2.4	1.5	0.7
	95% CI	ND	0.5–7.6	1.1–5.1	0.5–2.8	1.4–4.8	1.6–3.3	1.2–2.0	0.4–1.1

NOTE. The TBIMS does not contain data for persons under age 17.
Abbreviation: ND, no data.

of care in the TBIMS and CDDS were similar or (2) the effect of quality of care on life expectancy was outweighed by the effects of patient-specific factors: age, sex, and severity of disability.

Most of the CDDS life expectancies listed in table 1 are within 1 or 2 years of those reported by Shavelle.[7] The similarity reflects the fact that there have been no further major trends in mortality rates of long-term survivors of TBI. The new estimates reported here are more precise owing to the larger sample sizes in the expanded CDDS cohort. In addition, they are based on an updated statistical model, which was externally validated against the TBIMS cohort.[23] For these reasons, the new CDDS estimates both update and supersede those presented in our earlier work.

The CDDS and TBIMS life expectancies reported herein reflect patterns in mortality over the last 20 years. Analyses of both databases indicated that age-, sex-, and disability-specific mortality rates did not improve over the study period from 1988 to 2010. Although the CDDS and TBIMS are service-based registries (rather than population-based registries), there were no substantive changes in the data collection or case selection protocols over the study period. Hence, selection bias is unlikely to have accounted for this finding. These results suggest that, contrary to what might be expected, life expectancy for persons with moderate to severe TBI (and who have survived well beyond the acute postinjury period) has not increased over the last 20 years. Furthermore, because mortality rates of the general population have decreased, the SMR associated with moderate to severe TBI has increased over time. It would therefore be incorrect to compute the life expectancy of contemporary individuals by applying the SMRs computed from historical data to the current or projected mortality rates of the general population. Such an approach assumes, contrary to the evidence, that long-term mortality and life expectancy of persons with TBI has improved and would lead to overly optimistic values.

The reasons for the lack of improvement are not entirely clear. We note, however, that similar findings have been reported for persons with disabilities because of spinal cord injury (SCI).[26,27] Recently, DeVivo et al[28] reported that this phenomenon in persons with SCI was related to contrasting trends in specific causes of death. In particular, the decline in death rates associated with heart disease and cancer for the population with SCI was counterbalanced by an increasing incidence of death due to other causes such as diabetes and complications associated with prescribed medications. There were no trends in 2 causes of deaths known to play a major role in SCI mortality, namely, lung disease and infections. Whether similar trends explain the lack of overall improvement in life expectancy of persons with TBI should be investigated. Until evidence of significant trends in all-cause mortality emerge, the life expectancy estimates listed in table 1 should remain valid and reliable.

Specialist centers, including the TBIMS hospitals and CDDS regional centers, have long recognized TBI as a chronic condition that requires long-term management. The use of chronic disease management approaches with systematic changes in clinical care and community resources has been proposed as a means to improve life expectancy of persons with TBI.[29] Whether significant advances will be made remains to be seen.

Individual life expectancy calculations

The need to estimate life expectancy of an individual with moderate to severe TBI arises when counseling families or in the context of medical or financial planning for future care. Hence, the importance of accurate evidence-based estimates should be emphasized. The results summarized in table 1 may be considered a starting point for a more comprehensive analysis of an individual's life expectancy.

A key question of interest in practical work is not whether the individual can be narrowly classified into one of the columns of table 1 but whether that individual's condition as a whole is typical of the group. If the person's profile is markedly better or worse than the average, then some further adjustment to life expectancy may be indicated. To determine whether this is the case, other factors such as performance of activities of daily living, cognition and communication, comorbidities, general health, and behavioral risk factors should be considered. For example, in persons who do not walk or self-feed, one might consider more basic motor skills including the ability to sit or stand independently, the degree of functional hand use, continence, and communication skills. As shown in previous research,[11] dependence on a feeding tube is one of the most important markers of disability and therefore has a significant effect on life expectancy in this group. At the other end of the disability spectrum, we found (in supplementary analysis; data not shown) that among persons who were fully ambulatory, those who were able to live independently and engage in competitive employment lived longer (on average) than those who were not. In general, the life expectancies listed in table 1 should not be applied to persons who have made a complete recovery (ie, have no lasting disabilities, comorbidities, or psychiatric or behavioral issues) from their TBI.

Further numerical adjustments to the life expectancies listed in table 1 may be based on the research evidence related to comorbidities or lifestyle factors. For example, the research literature[30] can be used to quantify the effect of epilepsy on mortality based on the type (eg, generalized tonic clonic or not) and frequency of seizures. Similarly, there is an extensive literature on the effects of noninjury factors such as smoking and obesity. Numerical adjustments for such factors may be incorporated into life expectancy estimates using life table methods.

When empirical evidence on the effects of other factors is not available, the qualitative assessment of an experienced clinician may prove helpful. Again, if it is determined that the individual is better than the average with respect to such factors, then some upward adjustment may be reasonable, and vice versa. In this context, we caution against misinterpretation of the SEs in table 1. These standard errors indicate the statistical precision of the estimates; they do not reflect variation in other positive or negative factors and are thus not bounds on the life expectancy of particular individuals. To take an extreme example, the life expectancy of a person with TBI who also has a diagnosis of terminal cancer will undoubtedly be much lower than any value listed in table 1.

Although some of the large-scale TBI registries outside the United States have reported on survival probabilities, none has provided estimates of life expectancy per se. Unfortunately, the international registries do not yet contain detailed information on walking and feeding skills for large numbers of patients, which makes direct comparisons of the type described in this article impossible. Nonetheless, the data that are available have shown some broad similarities with regard to survival outcomes. For example, the recent Scottish study of McMillan et al[16] found that mortality rates of survivors of mild head injury were 4 times higher than those of community controls. This mortality ratio is broadly consistent with the SMRs for ambulatory adults with TBI in our study. Similarly, the hazard ratios reported in the Australian study of Baguley et al[12] based on the FIM and other factors appear to be broadly consistent with the results from the TBIMS.

It may be asked whether quality or availability of care under the international systems may be associated with better survival outcomes. Often the differences in life expectancies of the general population are cited in support of this. We note that the current life expectancy of the general population in California (80 years from birth) is equivalent to the current life expectancy of the United Kingdom and only slightly less than those of Canada or Australia. Furthermore, persons in the California-based CDDS cohort are provided all medically indicated care and long-term services (housing, physical and occupational therapy, speech and language therapy, and so on) through an entitlement by law, regardless of income or assets. In this respect, health care for persons served by the CDDS is very much like universal coverage systems in the United Kingdom, Canada, Australia, and other developed countries.

To summarize, the calculation of an individual's life expectancy is a complex task. Although table 1 provides a rational starting point, many other factors must be considered. For completeness, we remind the reader that the actual survival time of any particular individual may well be longer or shorter than the life expectancies reported herein. The life expectancy is the average survival time.

Study limitations

The limitations of the present study are largely similar to those identified in our companion article.[23] The walking-feeding disability groups are relatively broad, and the severity of a particular individual's disability may be significantly better or worse than the average in any one of these groups. A second limitation is the absence of noninjury factors, that is, lifestyle factors or other medical conditions, though such factors may be incorporated into an analysis of life expectancy with standard methods. Finally, we note again that the results of this study, which are based on the analysis of persons served at the TBIMS or CDDS centers, may not apply to persons with TBI so mild that they do not require inpatient rehabilitation or long-term services.

Conclusions

Estimates of life expectancy of survivors of moderate to severe TBI should take into account age, sex, and severity of disability. The life expectancies reported herein, based on the most recent CDDS data, supersede those given for the same comparison groups in previous articles. When properly compared on the basis of age, sex, and severity of disability, the CDDS and TBIMS databases yield similar estimates of life expectancy. This article may serve as a practical guide to survival prognosis of children, adolescents, and adults with TBI.

Suppliers

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

Keywords

Brain injuries; Life Expectancy; Mortality trends; Prognosis; Rehabilitation; Survival

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