
The Costs of Traumatic Brain Injury

Karla Thompson, PhD, Al Antony, MD, Adam Holtzman, MStat

In this time of limited resources and escalating health care costs, it is important to understand the “costs” associated with traumatic brain injury (TBI). Existing cost data are quite conservative, and most reports capture only part of the picture. This paper provides an overview of TBI-related costs and describes the limitations of the existing data. Some cost data specific to North Carolina are presented, as well as recommendations as to how we might acquire more comprehensive data regarding TBI.

Estimates of the costs associated with TBI are inextricably linked to the way cases are identified, which in turn generates incidence and prevalence data. There is no national registry for TBI and, at present, most states have no TBI surveillance systems. The Centers for Disease Control and Prevention (CDC) estimate the annual incidence of TBI at 1.5 million cases, with 50,000 deaths and approximately 230,000 hospitalizations each year. Every year, brain injury leads to long-term disability in 80,000 to 90,000 individuals, and a cumulative total of about 5.3 million Americans are currently living with disabilities resulting from brain injury.¹ Staggering as these numbers are, they almost certainly underestimate the true incidence and prevalence of disability due to TBI. In large part, this is because only those persons whose injuries led to hospitalization are counted. The one million people with less severe TBIs who are treated and released from emergency departments each year,¹ and unknown numbers of subjects with mild injuries, go unidentified because they seek outpatient treatment or no treatment at all. The residual impairments associated with mild TBI are generally minimal, but there are data to suggest that a significant percentage of so-called mild injuries lead to persistent and disabling symptoms.²

The financial costs associated with TBI represent the economic burden imposed on individuals, organizations, and societies by injury-related illness, disability, and premature death. Commonly identified costs include the direct costs for medical treatment, rehabilitation, and ongoing care, and the indirect costs of earnings lost to disability and death. The most comprehensive study of TBI-related costs was published in

1991. Using 1984-86 data from the National Hospital Discharge Survey, the National Medical Care Utilization and Expenditure Survey, the National Nursing Home Survey, and the National Council on Compensation Insurance Detailed Claim Information data bases, Max and her colleagues estimated the total annual costs of TBI at \$37.8 billion.³ A 1992 report prepared by Lewin-ICF for the National Foundation for Brain Research updated those figures to 1991 dollars (\$48.3 billion annually).⁴ Charges for acute hospitalization and inpatient rehabilitation accounted for less than 8% of the total, and all medical services constituted only 12%. The remaining 88% represents estimates of wages lost due to death and disability. Disability due to injuries requiring hospitalization accounted for \$31.7 billion in lost wages, and fatalities for another \$16.6 billion. The average lifetime cost per survivor was \$111,578, while the average cost per fatality was \$454,717.

There are reasons to believe that the cost estimates generated by Max et al. and the Lewin-ICF group are low. First, they did not attempt to estimate the costs of injuries that did not result in hospitalization. Second, their data did not include charges for cognitive rehabilitation, neuropsychological services, attendant care, transitional living centers, day treatment programs, supervised living services, community support services, special education services, services provided by friends and family, or insurance administration costs. Third, Lewin-ICF calculations used 1991 dollars. If we use the Consumer Price Index⁵ to translate the Max figures into 2001 dollars, we calculate that annual costs now exceed \$62 billion.

The Costs of Hospitalization

Current data yield wildly disparate estimates of the costs of hospitalization for TBI. The TBI Model Systems Project, a prospective, longitudinal multi-center study funded by the National Institute on Disability and Rehabilitation Research, indicates that acute care costs for treating TBI at Model Systems

Drs. Thompson and Antony are in the Department of Physical Medicine and Rehabilitation at UNC School of Medicine. Dr. Thompson is also in the Department of Psychiatry there. Mr. Holtzman is with the North Carolina Department of Health and Human Services in Raleigh. Address correspondence to Dr. Thompson at the Department of Physical Medicine and Rehabilitation, UNC School of Medicine, CB# 7200, Chapel Hill, NC. 27599-7255. E-mail: Karla_thompson@med.unc.edu.

facilities average \$98,612 per case, but the costs of inpatient rehabilitation average \$43,212 (these figures do not include physician charges).⁶ In contrast, Smith and his colleagues report elsewhere in this issue (see page 328) that there were more than 4,800 TBI-related hospitalizations in NC during fiscal year (FY) 2000, with resulting hospital charges of more than \$118 million (about \$25,000/admission). If these figures are complete, they suggest that charges for TBI-related hospitalizations in North Carolina are about one-fourth those generated by admission to Model Systems institutions. Possible explanations for this discrepancy include differences in admission criteria, length of stay, and scope of services. North Carolina's Charlotte Institute of Rehabilitation (CIR) is a new member of Model Systems but has not yet released any cost data. We expect that data from CIR will clarify the extent to which hospital care and associated costs for TBI in North Carolina are consistent with Model Systems standards.

Post-Hospital Care

We have only limited information about the costs of medical services that follow hospitalization for TBI. Max et al reported \$550 million in annual costs for ambulance and helicopter services, prescriptions, physician visits, physical therapy, and nursing home care;³ in 2001 dollars the figure would exceed \$907 million.⁵ Private insurance claims could provide more information, but are difficult to obtain. Publicly funded insurance programs are another source of information.

Medicaid is an entitlement program, jointly financed by state and federal governments and administered by the states. It normally covers charges for inpatient and outpatient hospitalization, physician services, laboratory, x-rays, home health, nursing home, and long-term care facilities for people with disabilities whose incomes fall below poverty levels. In 1981, the Health Care Finance Administration (HCFA) allowed states to develop Medicaid waivers in order to provide long-term and community-based services to people who would otherwise need institutionalization.⁷ In 1996, 36 million of over 225 million (16%) insured individuals were Medicaid recipients.⁸ Data provided by the North Carolina Department of Mental

Table 1. FY 2000 NC Medicaid paid claims by category of service

<i>Service</i>	<i>Dollars</i>	<i>Claims</i>
Ambulance	94,800	455
ER	1,713,400	819
Physician charges	2,383,200	12,167
Inpatient general hospital	23,920,000	940
Crossover services	120,100	40
Inpatient specialty hospital	1,534,200	34
Outpatient general hospital	935,100	1,522
Crossover services	203,300	281
Outpatient specialty hospital	157,100	67
Inpatient state mental hospital	14,700	2
Area MH/SA programs	326,000	104
Skilled nursing and swing beds	3,305,100	91
Intermediate care facilities – state	2,061,000	20
Intermediate care facilities – non-state	2,262,300	158
Home health	1,857,400	228
Personal care	250,200	23
DME	318,100	31
CAP-disabled	1,491,200	32
CAP-MR	2,018,100	48
Cap-children	266,800	3
TOTAL	\$47,128,218	\$17,361

Health, Developmental Disabilities, and Substance Abuse Services indicate that more than \$47 million was paid to cover 17,361 Medicaid claims for TBI-related diagnoses during FY 2000.⁹ Medicaid claims paid for selected categories of service are listed in Table 1. Inpatient medical hospital charges represented more than \$24 million, while outpatient hospital charges were approximately \$1.3 million. Notably, more than \$7.6 million was paid to skilled nursing and intermediate care facilities, more than \$1.8 million for home health care, and more than \$3.5 million for community alternative program (CAP) services. Physician charges (\$2.4 million) were a relatively small part (5%) of the total. There was no information about costs of medication.

Vocational Disability

The costs of medical care and related services for survivors of TBI are enormous, but they are dwarfed by the costs of disability. The CDC estimates that approximately 2% of the US population has some degree of disability due to brain injury;¹ that estimate is likely to be low because it includes only disability due to injuries that resulted in hospitalization. Collateral sources of information regarding vocational disability due to TBI include Social Security, Workers' Compensation claims, and Vocational Rehabilitation.

Social Security Disability (SSDI) and Supplemental Security (SSI) benefits are awarded to eligible disabled persons. Benefit amounts, which are based upon what the recipient has paid into the system during prior years of employment, may serve as proxy measures of income lost to disability. However, the Social Security Administration's (SSA) method of coding impairment is only loosely modeled on diagnostic codes from the 9th Revision of the International Classification of Diseases, Clinical Modification (ICD-9-CM), making identification of specific causes of disability problematic. The ICD-9 codes for intracranial injury with no evidence of skull fracture (codes 850-854) are presumably captured by the SSA impairment code 8540; however, the Office of Research and Statistics for Social Security reports that only 15,447 individuals across the entire country receive SSDI benefits and 7724 receive SSI benefits based on the 8540 impairment code (personal communication from Terri Dodson, Social Security Administration, September 4, 2001). Other SSA impairment codes that might identify cases of TBI do not necessarily match the ICD-9 codes from which they were derived. Approximately 62,807 people currently receive benefits referable to the 9070 impairment code, which the SSA defines as "late effects of injuries to the nervous system." Given the CDC's estimate of 5.3 million Americans with a TBI-related disability, either the SSA's method for coding impairments has no meaningful relationship to the methods used by the medical community, or only a fraction of those with TBI-related disabilities currently receive Social Security benefits.

Workplace injuries and illnesses that result in more than seven lost workdays or in permanent disability are reported to the North Carolina Industrial Commission. Injuries are classified on the basis of damage to various body parts, but ICD-9 codes are not used. Information for FY 1998 provided by the NC Industrial Commission's Office of Statistics indicates that injuries to the head and neck, which may include facial and cervical spine injuries as well as TBIs, resulted in payments for medical care in excess of \$1 million, and compensation for lost earnings in excess of \$2.6 million (personal communication from Linda Kirby, NC Industrial Commission, August 10, 2001). Compensation represents 66% of the worker's salary at the time of injury; thus, there are additional uncalculated costs in lost wages. These figures are based upon a total of 114 *closed cases*, for which costs averaged more than \$22,000/case. It should also be noted that the number of cases closed in 1998 is less than 10% of the number of total of ongoing cases (1,995) reported for Fiscal Year 2000.

Vocational Rehabilitation (VR) is a state agency within the Department of Health and Human Services. It is supported by state and federal funds. VR's mission is to help persons with disabilities obtain and maintain employment, and the agency funds a variety of services with that goal in mind. Data provided by VR indicate that in FY 2000 the state agency spent approximately \$965,000 on more than 1,013 North Carolinians with TBI-related disabilities (personal communication from Mike

Massey, Vocational Rehabilitation, August 15, 2001). A large portion of the budget (\$112,000) went to support independent employment for 65 clients. VR also paid approximately \$104,000 for medical, dental, and visual exams, medical reports, medication purchases, medical treatments, dental services, surgeries, and rehabilitation services. Goods and services paid for by VR included rent and utility payments (\$39,000), wheelchairs (\$22,000), vehicle modifications (\$25,000), and transportation (\$29,000). The largest TBI-related expenditure (\$270,000) was for tuition, educational fees, books and school supplies for more than 189 people.

As of April 1, 2001, 477 North Carolina students aged 3-21 years were receiving services under the TBI classification in approximately 250 traditional and charter schools, and in other state-operated school systems such as educational programs in hospitals and prisons (personal communication, NC Board of Education, August 10, 2001). Data regarding the costs of services are maintained by each local education agency (LEA) and have not been tabulated. There is no readily available information about the costs of training teachers to serve this special population, and the North Carolina University system does not track services provided to students with disabilities on the basis of specific diagnoses, so the costs of TBI-related education services remain unknown.

Public Spending

A report published by the Brain Injury Association, Inc., presented data on public spending on TBI for FY 1998.¹⁰ The study focused on federal and state spending for direct services (excluding hospitalization and nursing home placement), prevention, research, and surveillance. Non-public spending (by third-party payers) was not included. Reported expenditures of national public funds (Medicaid, VR, and Health Resources and Services Administration/Maternal and Child Health [HRSA/MCH]) totaled \$195.6 million for 46,341 identified cases; North Carolina spent an estimated \$6.24 million for 1,399 cases (\$3.8 million in federal and \$2.4 million in state funds). However, these numbers are suspiciously low, because NC state and federal Medicaid expenditures were reported to be \$1.1 million for a total of only six cases. Federal and state VR expenditures totaled \$4 million for 1,393 cases, while combined federal and state HRSA/MCH expenditures were \$1 million.

In 2000, the North Carolina legislature allocated \$1.5 million in discretionary funds to the Department of Health and Human Services' Divisions of Developmental Disabilities and Vocational Rehabilitation for TBI-related services and projects (personal communication, Office of Developmental Disabilities, September 21, 2001). The money was distributed to the Brain Injury Association of North Carolina (BIANC) and to community-based case-management, family support, and related services for TBI survivors; \$10,000 was allocated to the BIANC for establishment of a voluntary TBI registry.

A Closer Look: Life Care Plans

The physical, cognitive, and emotional sequelae of TBI vary greatly, even with injuries of similar severity. The resulting impairments and disabilities reflect the interaction of multiple premorbid attributes as well as the injury itself and early medical care. Although aggregate data can be used to estimate the average costs of injury, the true costs associated with any single TBI depend on the needs of the individual. Over the past two decades, Life Care Planning has gained popularity as a way to determine the severity of residual deficits in specific cases, and to estimate the costs of those deficits in terms of future health care needs, personal independence, and employment. Cost estimates use present-day costs, based on an assumption of private pay and non-negotiated rates, with no assumptions about the availability of collateral resources.¹¹ Life care plans are typically developed for attorneys on a fee-for-service basis and are more likely to be generated in cases involving personal injury litigation, but they provide a model for projecting costs that could be applied to any TBI survivor.

Conclusion and Recommendations

More than 5 million Americans live with TBI-related disabilities—an estimate that does not include disability due to injuries not requiring hospitalization. There is little dispute about the huge economic burden of TBI, but even the most frequently cited figures underestimate the true costs. Annual TBI-related costs now may well exceed \$62 billion without including costs of cognitive rehabilitation, neuropsychological services, attendant care, transitional living centers, day treatment programs, supervised living services, community support services, special education, or insurance administration costs. The average lifetime cost of a non-fatal TBI was estimated at less than \$112,000 in 1992, but the current combined costs of just acute hospitalization and rehabilitation at a Model Systems facility exceed this amount. And there are no models for estimating the costs of TBI to families. For those without medical insurance, charges for medical services are passed on to family members and/or society. Families may experience additional lost income when members must leave work to care for injured relatives. Additional costs may be incurred as a result of the survivor's inability to fulfill previous roles like parenting. Finally, family members of TBI survivors develop physical and mental symptoms themselves, the ultimate financial impact of which is unknown.

To date, the true incidence and prevalence of disability due to TBI in North Carolina are unknown. The state has no TBI registry, and physicians are not legally required to report TBI. Nonetheless, TBI is clearly a major public health problem. Paid North Carolina Medicaid claims, which probably represent only 15–30% of total medical service claims, amounted to more than \$47 million in FY 2000. Workers Compensation claims for cases closed in FY 1998 were \$3.6 million, but the number of current claims is more than ten times higher than that. Vocational

Rehabilitation expenditures approached \$1 million in FY 2000, and the state legislature allocated \$1.5 million for prevention, surveillance, and service-related projects.

Unfortunately, the true financial costs of TBI are probably incalculable. If we are to get any measure of the total impact of TBI, the needs for TBI services, and the success of prevention efforts in North Carolina, the state must develop surveillance systems that identify and track emergency department visits, injuries that do not result in hospitalization, and long-term outcomes. Much of the information needed to develop such a surveillance system already exists in isolated databases like the North Carolina Trauma Registry; the state Regional Advisory Councils (which will include basic Emergency Department information); Premise, an ambulance data base; the Medical Examiner's Office data base; and the state Hospital Discharge data base maintained by the Center for Health Statistics. In addition, VR, Developmental Disabilities, the North Carolina Industrial Commission, the public school and university systems, and even private insurance companies could participate in a coordinated effort to gather accurate data about TBI-related deaths, disability, and service needs. However, none of these agencies is likely to take the initiative in integrating data from multiple sources. In the absence of a legal mandate identifying TBI as a reportable injury, the NC Brain Injury Association may have to lead the way in efforts to generate current, comprehensive, and meaningful data regarding the costs of TBI in North Carolina.

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