The Traumatic Brain Injury Model Systems of Care: A Review of Recent Accomplishments

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Santa Clara Valley TBI Model System of Care

The 1997-2002 grant cycle for the NIDRR-funded Traumatic Brain Injury Model Systems of Care (TBIMS) ended on September 30, 2002. The TBIMS program has grown from an initial cadre of 5 model system centers in 1987 to 17 centers in 1998, with increasing recognition of traumatic brain injury as a leading public health issue.

Each TBIMS is comprised of the following components: a comprehensive system of acute and rehabilitation care; contribution of patient data to a TBI National Database; prospective and annual follow-up data collection; a local center-based research program addressing key areas of TBI rehabilitation guided by NIDRR research priorities; and dissemination of findings to professionals, individuals with TBI, and families. The comprehensive system of care must extend from the onset of injury, through the acute medical and rehabilitation phases of care, and into the community re-entry stage. The TBIMS should demonstrate coordinated, cost-effective neurotrauma and rehabilitation services to maximize recovery and reintegration through early effective and efficient intervention, a sophisticated multi-disciplinary team of TBI professionals, and support services available in the community to facilitate optimal level of physical and psychosocial functioning.

The TBI National Database is a prospective, longitudinal data collection effort with the goal of examining the natural history of recovery and outcomes throughout the lifespan of individuals with moderate to severe TBI. Traumatic brain injury is operationally defined as “damage to brain tissue caused by external mechanical forces as evidenced by at least one of the following: loss of consciousness; post-traumatic amnesia; skull fracture; objective neurological findings of brain trauma.” (TBIMS Syllabus, 2003). The additional inclusion criteria for the national database are: older than 16 years of age; present alive to the TBIMS emergency department within 24 hours of injury; receive both acute care and rehabilitation services within the TBIMS; and provision of informed consent. The data that has been collected include: pre-injury demographic and psychosocial characteristics; injury etiology and severity; acute medical and rehabilitation interventions; functional status at admission and discharge; levels of neuropsychological functioning and discharge disposition. Individuals are contacted on an annual basis and queried concerning functional and psychosocial outcomes. Currently, there are over 4000 individuals with TBI who have been enrolled in the National Database.

The priorities that guided the 1997-2002 research program were formulated by NIDRR after synthesizing input from consumers, professionals, federal and state agencies, and constituents, as well as findings from the TBIMS and other organizations involved in providing services for persons with TBI. Decreasing lengths of stay, changing patterns of inpatient rehabilitation service delivery, and the increasing reliance on outpatient and community reintegration programs were the impetus for the first NIDRR priority which required the TBIMS to investigate the efficacy of alternative methods of service delivery interventions after inpatient rehabilitation discharge. The second priority -

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Spaulding Rehabilitation Hospital (SRH), located in Boston, Massachusetts, is a 296-bed hospital certified as a long-term acute care hospital. Its rehabilitation programs include those that care for patients with brain injury, spinal cord injury, stroke, amputation, orthopedic and arthritic conditions, chronic pain, heart disease, pulmonary disease, and other medical conditions, and includes a pediatric program housed at the nearby Massachusetts Eye and Ear Infirmary. SRH is the home of the Harvard Medical School Department of Physical Medicine & Rehabilitation (PM&R) and its PM&R residency training program.

The Spaulding TBI Model System

The Spaulding TBI Model System (TBIMS) provides a comprehensive spectrum of care for people with TBI through the collaborative efforts of three hospitals that are part of Partners Health Care System, Inc. and three organizations that operate a variety of postacute rehabilitation programs.

Partners Health Care System includes two Level I Trauma Centers affiliated with Harvard Medical School and one rehabilitation hospital, SRH. The Level I Trauma Centers, Massachusetts General Hospital and Brigham and Women’s Hospital, participate in the City of Boston’s Medflight system of helicopter transport of injured patients from the field to the Emergency Departments. The associated postacute rehabilitation programs include Community Rehab Care, Massachusetts Mentor, and the Commonwealth of Massachusetts Statewide Head Injury Program. SRH lies at the center of the Model System network, with physician or other staff liaisons to every component of the system. Mel Glenn, M.D., Director of Outpatient and Community Brain Injury Rehabilitation, is the Spaulding TBIMS Project Director.

The Spaulding TBIMS Brain Injury Rehabilitation Program includes a 38-bed CARF-accredited inpatient unit. David Burke, M.D. is Medical Director. A dedicated team of nurses and allied health care professionals cares for the patient and implements the rehabilitation program. Marilyn Price Spivack, founder of the Brain Injury Association of America and the Massachusetts Brain Injury Association, is SRH’s Neurotrauma Outreach Coordinator. She provides support and advocacy for the families and other loved ones of patients on the unit. The Brain Injury Rehabilitation Program admitted 76 patients with TBI during the first six months of the new grant cycle that began on October 1, 2002.

The Project Advisory Board meets semi-annually to provide direction and advice to the project leadership. The board is made up of a diverse set of providers and consumers of services for people with TBI. Marilyn Price Spivack is the board’s Chairperson.

The 1998-2002 Funding Cycle

The Spaulding TBIMS recently completed a productive four-year grant period from 1998-2002. The TBIMS has completed research studies on the incidence of depression among outpatients, the cut-off score on an apathy measurement scale, the use personal digital assistants as memory aids, methylphenidate’s effect on blood pressure and heart rate, useful field of view as an outcome measure, outcomes of TBI vs. hypoxic encephalopathies, and sleep-wake cycles on an inpatient unit. Ongoing projects include surveys on the characteristics of community integration programs, a trial of teleconferencing for supervision of a host home rehabilitation program; and studies of the effect of a community skills group on outcome, the use of palmtop computers for people with TBI, the use of modafinil to treat attentional problems, and the use of voice-activated computer software in people with TBI who are dysarthric.

Spaulding TBIMS staff produced 23 articles and chapters on subjects related to TBI during that time, for example:


The TBIMS team presented numerous papers, posters, lectures, and workshops to both healthcare professionals and consumers. The TBIMS produced four annual newsletters oriented towards both consumers and professionals. Newsletters can be viewed on our website [www.spauldingrehab.org].
The 2002-2007 Funding Cycle

During the first six months of the new funding cycle, 34 subjects were enrolled in TBIMS National Database. Follow-up has continued on subjects entered during the last cycle.

The Spaulding/Partners TBIMS major research endeavor for the new cycle is a study entitled "Regional Cerebral Activation on fMRI as a Predictor of Outcome Following TBI". Gary Strangman, Ph.D. is the principal investigator (PI). This study will take an important step toward the development of functional neuroimaging as a tool that may guide cognitive rehabilitation for individuals with TBI. Dr. Douglas Katz and Healthsouth Braintree Rehabilitation Hospital will collaborate with the TBIMS on this study. Functional magnetic resonance imaging (fMRI) will be used to detect activation in prefrontal cortex and other areas of the brain. The study consists of cross-sectional and longitudinal components:

1) The cross-sectional component will assess regional brain activation during the memorization of word lists, both under undirected (spontaneous) conditions and following training and cueing to use a categorization strategy. Subjects with TBI and non-TBI controls will be compared with respect to the activation of prefrontal cerebral cortical regions known to support the use of such a strategy.

2) The longitudinal component will study the ability of the fMRI findings to predict outcome among people with TBI who participate in a community integration program with a cognitive rehabilitation focus. The investigators will use regression models that account for other known predictors of outcome.

Therese O’Neil Pirozzi, Sc.D., the Associate Project Director, will be the PI on a study investigating the test-retest reliability of the Virtual Planning Test, a measure that attempts to assess executive function with a more ecologically-valid approach than do other neuropsychological tests. Additionally, in collaboration with other NIDRR-funded TBIMS sites, SRH TBIMS is conducting research on three other topics: mortality, aging, and recovery from co-existing TBI and spinal cord injuries. Dr. Glenn is PI of the latter.

For more information call our Project Coordinator, Elizabeth Selleck, at 617-573-2381 or visit our website. (www.spauldingrehab.org/tbims)

University of Washington TBI Model System of Care
Seattle, Washington

In the northwest corner of the United States, the University of Washington Traumatic Brain Injury Model System has been thriving for four years. As part of the Level I Trauma System at Harborview Medical Center and UW Medical Center, the UW TBIMS is part of a trauma system that receives patients from five states (Washington, Wyoming, Alaska, Montana, and Idaho). At UW Medicine, we provide a comprehensive, integrated continuum of services to persons with acute and chronic TBI. During our first four years as a Model System, we have been a major contributor of high-quality data to the Model System National Database and have forged strong relationships with other Model System centers, consumer organizations, and state agencies. The research track record of the investigators at this center is broad and respected, and the UW, as a national leader in rehabilitation research, provides excellent facilities, financial support and grant administration.

Clinical Services.

The UW Department of Rehabilitation Medicine has been named one of the top three rehabilitation centers by U.S. News and World Report for over 10 years. Our 55 rehabilitation beds at the two centers are jointly accredited by CARF. In addition to state of the art inpatient services for persons with brain injuries, we are known for our group therapy and educational venues and the applications of rehabilitation technology to education and work. Examples of this are the DO-IT program (Disabilities, Opportunities, Internetworking, Technology) for pre-college and college students to achieve academic success and the Project with Industry program providing job development and placement. Because of our largely rural catchment area from an extremely large land mass, we have been involved in the delivery of care to geographically distant patients and consultation to rural patient care providers via our telecommunications projects and MedCon (toll-free consultation phone line). Our major research project from the preceding grant cycle focused on providing telephone-based services to Model System participants resulting in improved overall function and quality of life.

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Dissemination

At the UWTBIMS, we understand that our consumer dissemination efforts are a top priority. In order to empower our consumers, we are continuing to enhance a dynamic website with consumer and professional information and links to many sources (http://depts.washington.edu/rehab/tbi/index.html). In addition, we have cosponsored a highly successful consumer fair with the Brain Injury Association of Washington and the Division of Vocational Rehabilitation. Recent additions include an UWTBIMS electronic newsletter with education, news, research updates, and consumer contributions. Numerous publications and presentations in professional and consumer journals (including Archives of Physical Medicine and Rehabilitation, Journal of Clinical and Experimental Neuropsychology, Journal of Neurotrauma, Journal of Head Trauma Rehabilitation) and meetings that have been a hallmark of UWTBIMS.

Model System Data

Although we have only been a part of the TBI Model System study for a relatively short period, our contribution to the National Database has been solid and distinguished. For example, in addition to the high number of submissions, we rank first for submission of neuropsychological testing for all the years we have participated (96%) despite having the second largest enrollment of the “new” centers.

The UWTBIMS research team members also have a commitment to collaborate with other centers to improve and refine the National Database. Presently, we are trying to identify a statistical model to account for the profile of subjects that are most frequently lost to follow-up.

Research

Research at the UW is a centerpiece of our department and the TBI program. The UW Department of Rehabilitation Medicine ranks in the top two for NIH funding and in the top three in overall funding for rehabilitation departments in the U.S. The investigators for UWTBIMS have a long track record in TBI research and are internationally recognized for their work on the natural history of recovery, neurobehavioral outcomes, large clinical trials, interventions to improve vocational outcome, alcohol treatment, and the impact of public policy on rehabilitation. They are also known for their ability to conduct rigorous controlled studies, to attain excellent rate of follow-up in longitudinal studies, and to manage large databases. Dr. Sureyya Dikmen was the 2000 Caveness Award winner from the Brain Injury Association of America. In addition to the Model System, our team members currently have active federally funded studies on Magnesium Sulfate and Acute TBI, fMRI Study of Executive Function in Acute TBI, and Sertraline for Treatment of Depression after TBI.

In addition to the national data we collect, we have multiple TBI studies as part of our Model System. One of our recent efforts is our Exercise and Depression study that is just getting underway. This will be one of the first controlled studies in this area; it is a particularly important topic as the TBI population is often intolerant of antidepressant medication, poorly responsive to psychotherapy, and financially challenged. In this study, we will provide ten weeks of exercise classes with a physical trainer to the experimental group and will offer the classes to the control group after completion of the outcome assessment. The participants will receive motivational interviewing as part of the intervention in order to maintain healthy exercise patterns and community participation. The effect of exercise on mood, anxiety, sleep, pain, and overall function will be assessed.

Another research project at UWTBIMS studies the risk of unemployment and identifies the characteristics of those persons with TBI who successfully return to and retain employment in contrast to those who will need exceptional intervention. We also look at job demands and how they relate to abilities to maintain jobs. Researching this is an essential step in the design of future work intervention studies to achieve quality and stable employment for persons with TBI. In a similar vein, one of our studies examines the effect of Medicare’s prospective payment system for inpatient rehabilitation for persons with TBI on access to services, reviewing the outcomes and effects on discharge from acute rehabilitation.

Community Integration

In addition to our outstanding medical care and research history, perhaps some of our finest contributions are those of our TBI survivors. The UWTBIMS has committed to including those with TBI in all aspects of our Model System, including participation in our public education efforts and as research personnel. We are also working closely with our newly funded State TBI Implementation Grant Advisory Board and the BIA Washington in coordinating and improving services for those with TBI and their families.

For contact information about the TBIMS programs, projects and associated publications visit our website:

www.tbindc.org
“identify and evaluate interventions that can improve vocational outcomes and community integration” was developed in recognition of the shift toward psychosocial and vocational rehabilitation services, as need for physical rehabilitation diminishes as time progresses from the initial recovery phase (1st 6-12 months). The third priority, “to develop key predictors of rehabilitation outcome at hospital discharge and at long-term follow-up,” recognized the increasing requirement for markers of long-term recovery and a better estimation of the time course of recovery from TBI for the survivor, his/her family, and third party payors and primary care physicians who may not be familiar with the degree of recovery to be expected. The fourth priority, “to determine relationships between cost of care and functional outcomes,” was based on the increasing awareness of the need for cost-containment while acknowledging the importance of providing state-of-the-art care. The final priority -- “to examine the implications of violence as a cause of TBI on treatment interventions, rehabilitation costs, and long-term outcomes” -- recognized that the percentage of TBI-related deaths due to violence, one of the leading causes of TBI, has been steadily increasing over the years, and is now the second leading cause of TBI, following vehicular accidents.

The resultant TBIMS research programs collectively contained 34 collaborative studies and 140 local projects. The collaborative studies ranged from those that utilized the power of the TBI National Database as a source of longitudinal data on a large number of individuals with TBI to projects that a group of TBIMS with similar interests joined together to increase sample size and methodological rigor. The local projects were diverse in nature, encompassing demonstration activities, scale development and validation, intervention assessment, and pharmacological trials. All of these projects, and many more that came to fruition in collaborative efforts to “mine the database”, resulted in prominent participation of the TBIMS program at national and international conferences, such as the Brain Injury Association of America annual meetings and the American Congress of Rehabilitation Medicine, as well as in coordination of the 1st Federal Interagency Conference on TBI held in Bethesda MD in December 1999. Written dissemination, both consumer-oriented and professional-level, was as dynamic, culminating in the February 2003 issue of Archives of Physical Medicine and Rehabilitation, entitled “Special Issue - Traumatic Brain Injury: Current Research Outcomes” in which 18 of the 20 articles were research studies from the 1997-2002 TBIMS program.

The impact of the TBIMS program grew substantially throughout the 1997-2002 grant cycle in terms of the body of research and its impact on the scientific, professional and consumer communities. New initiatives using the power of the world-wide web served to further disseminate the activities and findings of the TBIMS program. The TBIMS Research and Publication Registry (www.tbimdc.org/registry), is a searchable website that includes detailed listings of the more than 200 research projects and over 400 publications that have resulted from the TBIMS program. The Center on Outcome Measurement in Brain Injury – COMBI (www.tbims.org/combi) – is a collaborative, web-based project that contains detailed information on 21 outcome and assessment measures that are used in brain injury research and clinical assessment. Both of these websites, updated on a regular basis, have proven immensely popular both within the United States and throughout the world.

As we move through the 2002-2007 funding cycle, it is hoped that the ever-growing database, long-term follow-up studies, innovative center-based and collaborative research studies on new methods of assessment and intervention continue to impact all who are involved in the practice of brain injury rehabilitation and the persons and family members we serve.

REFERENCES

Measuring Change in Neuropsychological Functioning

Scott R. Millis, Ph.D., ABPP, TBI National Data Center

The neuropsychological consequences of traumatic brain injury (TBI) in adults have been relatively well documented. Reduced capacity for new learning, slowed information processing, and disruption in complex integrative functions have been reported, although the extent and pervasiveness of impairment seem to be related to the initial severity of the TBI as well as the time post-injury at which the individual is assessed (Dikmen, Machamer, Winn, & Temkin, 1995). However, long-term neuropsychological recovery is less well understood. Does recovery continue several years following injury? Is recovery uniform across individuals and neuropsychological domains? Previous studies have been hampered in answering these questions by small samples, limited follow-up, or inadequacies in statistical design. Typically, investigators have calculated mean test scores for comparisons, collected data at only two time points, and examined persons with TBI at 2 years post-injury or less (e.g., Dikmen et al., 1995; Drudge, Williams, Kessler, & Gomes, 1984).

To examine the recovery of learning and memory ability following traumatic brain injury, we took a sample of 50 participants from the TBI Model Systems database who completed a memory test (RA VLT: Rey Auditory Verbal Learning Test) at least four times at yearly intervals over a five-year period. Descriptive data for the sample appears in the following table.

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<tr>
<td>Coma (days)</td>
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<td>50</td>
<td>46</td>
<td>10.57</td>
<td>6</td>
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<td>9</td>
<td>148</td>
<td>51.13</td>
<td>38</td>
<td>35.65</td>
</tr>
</tbody>
</table>

As noted, investigators have generally studied change by comparing the average performance on an outcome variable over time. For example, using the multivariate approach to repeated measures, we failed to find a statistically significant difference in RA VLT performance over the five-year period (Wilks’ L = .35, F = 1.36, p = .42). Indeed, visual inspection of the means and their associated 95% confidence intervals suggests little change over time. (Figure 1)

Yet, visual inspection of individual patient performance on the RA VLT suggests significant heterogeneity across people and time that is missed when mean or average performance alone is analyzed (Figure 2). Indeed, standard repeated measures analysis does not allow one to measure differences in rates of change among individuals but treats these differences as error (Raudenbush & Bryk, 2002).

We can begin to make sense of this heterogeneous pattern of RA VLT performance by examining an overlay plot of the individual profiles and the average trend using a spline, as shown in the next graph. The average trend shows that RA VLT performance is fairly consistent over time, but there may be several factors that affect where people “begin” on the RA VLT and the types of growth trajectories that they demonstrate, i.e., age at injury, gender, and level of disability at the time of admission to inpatient rehabilitation (Figure 3). To highlight group profiles, smoothed lines representing different subgroups were fitted. To define the age subgroups, the levels of age were collapse into quartiles. The youngest patients tended to out-perform the other age groups on the RA VLT (Figure 4). Initial level of disability was assessed with the Disability Rating Scale (DRS). The DRS also grouped into quartiles. The relationship between DRS and RA VLT appears much more complex (Figure 5). However, the relationship between gender the RA VLT appears more straightforward, i.e., women tend to do better than men on the RA VLT (Figure 6).
This exploratory data analysis assists us in identifying general trends within people, may detect nonlinear change over time, provides information about variability at different time points, and helps us in identifying variables that might affect change over time. In the next phase of analysis, we will use the information gain in this exploratory data analysis to employ a new approach to the analysis of change, the *linear mixed model*. As we will discuss, it has many advantages over the standard analysis of variance that we illustrated in our initial analysis.

**REFERENCES**


