

Traumatic Brain Injury

Facts and Figures

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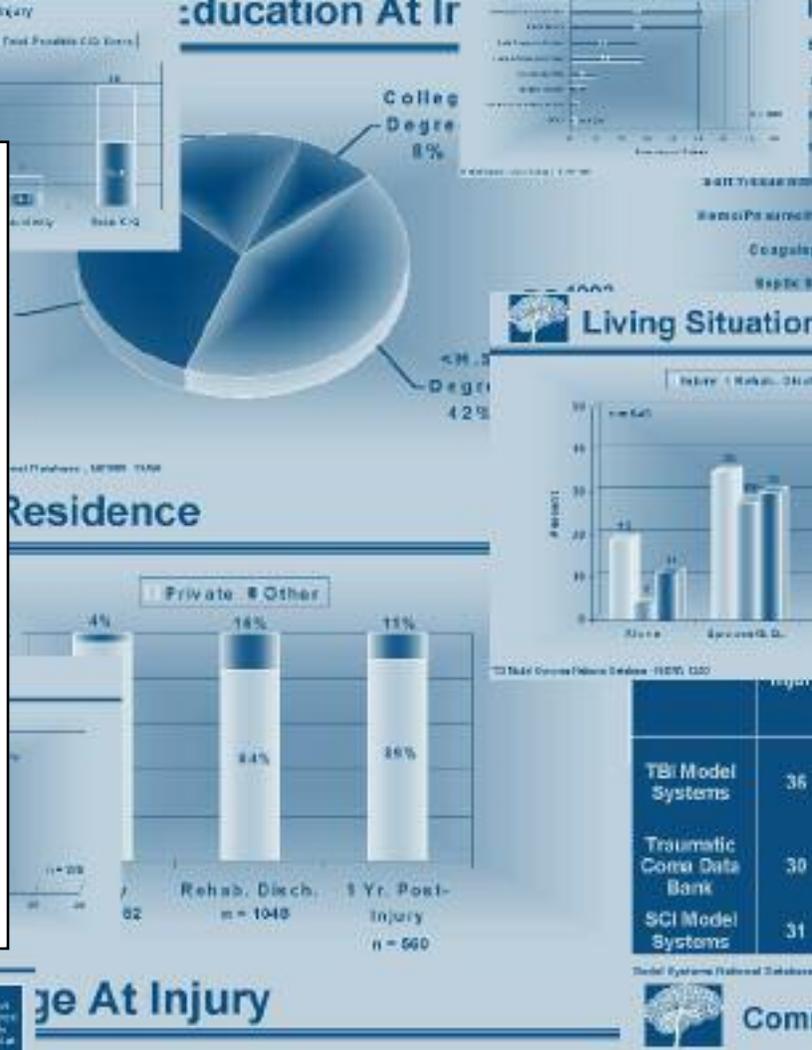
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Traumatic Brain Injury

Facts and Figures

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Moving Into New Research Models For the Traumatic Brain Injury Model Systems: Collaborative Modular Projects

Tessa Hart, PhD

Moss Traumatic Brain Injury Model System

The mission of the Traumatic Brain Injury Model System program is to "...improve the lives of persons who experience TBI, their families and their communities by creating and disseminating new knowledge about the course, treatment and outcomes relating to their condition." *Creating new knowledge* implies a primary focus on the research programs of the TBIMS. These programs include local projects funded separately for each TBIMS center, as well as collaborative projects that capitalize on the shared expertise and interests of TBIMS investigators across centers, and on the shared commitment to collecting, analyzing and interpreting the longitudinal data in the National Database (NDB).

Until the current (2002-2007) TBIMS cycle, the NDB included extensive measures of outcome and detailed medical data that were collected by all TBIMS centers. In keeping with this, most collaborative research "mining" the NDB has been retrospective in nature. Collaborative research on the NDB has provided valuable insights into the factors affecting the many outcomes of TBI, as well as rich descriptions of the longitudinal changes seen after injury. (For a searchable electronic bibliography of NDB studies as well as reports of local TBIMS research, see the TBIMS Publication Registry at www.tbimdc.org.) However, in recent years, the potential for collaborative multi-center research in the TBIMS has been enhanced with the introduction of a new type of study: collaborative modular research projects.

Collaborative Modular Research

The development of modular research projects has been an outgrowth of the "maturation" of the TBIMS program, as NIDRR and Project Directors seek to refine the purposes of the program and the sophistication of research designs. Early in the current (2002-2007) funding cycle, continuing a process that was begun in the previous one, the number of variables contributed indefinitely, by all centers, to the common longitudinal database was dramatically reduced. At the same time, a decision was reached to develop a new model for prospective collaborative research—a modular approach in which clusters of centers could contribute data germane to more specific projects, over a more limited time frame. All TBIMS centers would continue to collect basic data on all participants enrolled in the NDB, but could elect to participate in modular studies depending on their own research interests and available resources. These data "modules" could be used to address *a priori* questions and hypotheses, as well as additional questions related to the same topic that might arise later.

The idea of modular research was discussed and implemented over a period of more than a year, during which both the conceptual and logistical implications were worked out for a first set of five projects (described in a later section of this article) which were to begin during the current cycle.

Table 1 summarizes the main differences between the new modular research projects and the more traditional collaborative research projects using the TBIMS database.

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JFK - Johnson Rehabilitation Institute TBI Model System Edison, New Jersey

The JFK-Johnson Rehabilitation Institute, established in 1974, is a major component of Solaris Health System – one of the most comprehensive health care networks in New Jersey. Johnson Rehabilitation Institute (JRI) includes 94 in-patient beds in a separately licensed hospital attached to the Anthony M. Yelencsics Community Hospital. Together they comprise the JFK Medical Center, a private, not-for-profit community hospital. JRI offers a number of specialty programs and outpatient clinics, including orthopedics, sports medicine, cardiac rehabilitation, women's health, and pediatric rehabilitation. JRI is the Physical Medicine and Rehabilitation

Department of the University of Medicine and Dentistry of New Jersey – Robert Wood Johnson Medical School. As an affiliate of Solaris Health System it enjoys a close working relationship with the New Jersey Neuroscience Institute at JFK Medical Center.

Brain Injury Rehabilitation

In 1979, JRI established a dedicated, comprehensive program devoted to the rehabilitation of people with traumatic brain injury (TBI). At that time, JRI was one of only a handful of fully-specialized brain injury rehabilitation programs in the country, and a pioneer in providing specialized services to address the physical, cognitive and psychosocial needs of people with TBI. The initial component of JRI brain injury rehabilitation, the **Cognitive Rehabilitation** department, was devoted to providing post-acute, community-based treatment, particularly for those survivors of TBI who exhibited persistent cognitive limitations despite good neurologic recovery. In 1984, the Center for Head Injuries was established through the addition of a dedicated 26 bed in-patient Brain Trauma Unit. Since its inception, the **Brain Trauma Unit** has offered highly specialized diagnostic and treatment services for people with profound disorders of consciousness, as well as acute rehabilitation for those with severe TBI. Over the next five years, brain injury rehabilitation expanded its continuum of care to include an additional 45 bed **Extended Recovery Unit**; an eight bed, residential **Transitional Living** component; the **Neuropsychology Clinic** for the treatment of patients with mild TBI; and a number of after-care programs that allow us to provide continuing care to patients within their community throughout the course of recovery. The JRI TBI Model System is affiliated with Level I Trauma Centers at Robert Wood Johnson University Hospital and University Hospital-Newark and Regional Trauma Centers at Morristown Medical Center and Jersey Shore Medical Center.



TBI Model System of Care at JFK-Johnson Rehabilitation Institute

JRI began participating in the NIDRR TBI Model System program in 2002. Our recognition as a TBI Model System recognizes the existing continuum of care for people with TBI. Our local research projects being conducted during this cycle of funding reflect our history of clinical research and breadth of interests.

Disorders of Consciousness

Our prior research in this area has been devoted to the development of specialized neurobehavioral techniques, such as the Coma Recovery Scale-Revised (CRS-R) and exploration of prognostic factors related to recovery from coma, vegetative state, and minimally conscious state. We have initiated a local research project for *Investigating the Utility of Functional MRI in Assessing Cognition, Predicting Outcome and Planning Treatment in Persons Diagnosed with Minimally Conscious State (MCS)*. The main objective of this project is to study the impact of diagnostic innovations, such as the use of functional MRI (fMRI) on management of rehabilitation outcomes for patients with disorders of consciousness. The project has four specific goals. The first is to compare fMRI activation patterns between patients diagnosed as being in MCS with the activation patterns of neurologically normal controls. The second is to determine the relationship between neurobehavioral ratings of language and visual functions and cerebral activation patterns in patients with MCS. The third goal is to determine whether these cerebral activation patterns predict recovery of specific language and visual functions, as well as disability at one year post-injury. The final goal is to evaluate whether information obtained from fMRI can inform rehabilitation treatment planning in fMRI patients. The questions addressed in this study will have direct impact on family members' need for information regarding the expected course of recovery and potentially inform decisions regarding life-care plan-

Johnson Rehabilitation Institute

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ning. The knowledge derived from this study, including the development of a new fMRI application, may have direct implications for clinicians involved in the care of individuals with MCS.

In 2003, JRI was awarded a TBIMS Collaborative Grant from NIDRR to evaluate the effectiveness of amantadine hydrochloride for treating patients in vegetative (VS) and minimally conscious states (MCS). This is a multi-center, prospective, double-blind randomized controlled trial that is expected to involve more than 180 patients diagnosed with VS or MCS. The Disability Rating Scale serves as the primary outcome measure with the CRS-R serving as a supplementary measure. There are eight institutions participating in this international, multi-center study, including the TBI Model Systems at Moss Rehabilitation Institute (Pennsylvania) and Methodist Rehabilitation Center (Mississippi).

Cognitive Rehabilitation

The development of interventions for cognitive disability after TBI and evaluation of the effectiveness of cognitive rehabilitation represent long-standing and active concerns at JRI. Although there is generally consensus that improvements in life participation and subjective well-being represent the ultimate outcomes of cognitive rehabilitation, relatively few studies have directly assessed these outcomes. There is also evidence that the greatest benefits of cognitive rehabilitation, including clinically significant improvements in community integration, can be achieved through comprehensive-holistic programs that integrate cognitive and psychosocial interventions. In our initial prospective, non-randomized study of intensive-holistic cognitive rehabilitation we have demonstrated that patients who are many years post-injury and have been unable to resume effective social or vocational functioning can make significant improvements in their neuropsychological functioning and community integration. This study was also the first published report of cognitive rehabilitation in which a measure of quality of life was used as a direct outcome measure. This study found that satisfaction with community functioning was a distinct and separable outcome from objective measures of activity and participation. It also suggested that the individual's satisfaction with his or her cognitive functioning was an important predictor of community integration.

As part of the current TBIMS funding cycle, we are conducting a controlled study of *Intensive Cognitive Rehabilitation versus Standard Neurorehabilitation for Individuals with TBI*, who are referred either directly from acute rehabilitation or from the community. This project is a prospective, randomized controlled trial in which all patients will be assigned to receive either an intensive-holistic program of rehabilitation emphasizing the treatment of cognitive disability and interpersonal functioning within a therapeutic milieu, or a "standard" program of brain injury rehabilitation. The primary outcome measure of the study is the proportion of patients who demonstrate clinically significant improvements on the Community Integration Questionnaire. Outcome will also be assessed with a range of relevant health-related outcome measures, including neuropsychological functioning, satisfaction with functioning, perceived self-efficacy and perceived quality of life, and a patient-centered view of change after rehabilitation.

Quality of Life

While we are concerned with the effectiveness of rehabilitation services for increasing social participation and quality of life, we recognize that the needs of persons with TBI persist following rehabilitation. In fact, the needs of persons with TBI are likely to change in accordance with their life circumstances and the long term needs of individuals will vary accordingly. Given the considerable variability that characterizes the long-term outcomes of persons with TBI, it is apparent that a full understanding of the quality of life after TBI requires measurement and intervention strategies that are sensitive to the unique experiences of each individual. Our third project addresses the question of *What Does it Take to Live a Full and Fulfilling Life after TBI?* through a combination of qualitative and quantitative assessment procedures. Qualitative methods are particularly appropriate in capturing the individual's perspective after TBI, and should contribute to the investigation of the rehabilitation process and outcome. While a valuable understanding of the person's perspective may evolve through qualitative inquiry, this approach will not be viable in many situations in which it is still desirable to obtain information regarding the individual's subjective well being. At present, there are no measures of quality of life that have been developed specifically for persons with TBI. The study also incorporates a number of quantitative measures to assess the individual's satisfaction with functioning, perceived self-efficacy, and perceived quality of life. Through the combination of qualitative and quantitative methods, we expect to obtain a fuller understanding of the factors contributing to quality of life after TBI, and its assessment. People with TBI who are living in the community will be asked to complete the qualitative interview, quantitative measures, or both. Since many of these people have previously received rehabilitation, we will also be able to examine the relationship between rehabilitation outcomes and subjective well being. For example, we are particularly interested in how community participation and subjective well-being may be mediated by the person's self-efficacy beliefs. Our initial experience with this study suggests that the qualitative interview will allow additional perspectives to emerge regarding the process of rehabilitation after TBI, and the aspects of rehabilitation that patients find most valuable.

Our Mission to the Community

Throughout its 25 year history of brain injury rehabilitation and research, JFK-Johnson Rehabilitation Institute has remained sensitive to the needs of people within our community. JRI provides a number of community education, outreach and support services to people with TBI throughout the entire course of recovery, their families, and the providers who serve them. Representatives of the JRI TBI Model System also serve the interests of people with TBI through participation on the **Brain Injury Association of New Jersey** Board of Directors and the **New Jersey State Commission on Brain Injury Research**. All of the clinical and research activities at JRI reflect a simple mission: to provide quality rehabilitation that improves people's well-being and participation in life.

More information about the JFK-Johnson Rehabilitation Institute TBI Model System of Care can be found at www.njrehab.org/tbims.

North Texas Traumatic Brain Injury Model System Dallas, Texas

The North Texas Traumatic Brain Injury Model System (North Texas-TBIMS) represents a collaborative effort between the two largest hospital systems in North Texas - The University of Texas Southwestern Medical Center Affiliated Hospitals (UTSW) and Baylor University Medical Center (BUMC). Due to their central location and reputation, UTSW and BUMC serve a large catchment area including the northern and western regions of Texas, and the surrounding states of Oklahoma, Arkansas, and Louisiana. The North Texas Area, with 75 counties, is the most populous region in the state and accounts for a substantial portion of traumatic brain injury (TBI) cases in Texas. These two Level I trauma centers admit over 80% of all TBI patients in the North Texas area and share a commitment to clinical research in the field of TBI.

UTSW, with 4 Nobel Prize winners and 15 members of the National Academy of Sciences, is noted for cutting edge research. BUMC has a track record of excellent clinical management of TBI and recently celebrated 100 years of service in Dallas. Following acute care at these outstanding institutions, patients in the North Texas - TBIMS receive their rehabilitative care at Parkland Health and Hospital System (PHHS), Zale-Lipshy University Hospital (ZLUH) or Baylor Institute for Rehabilitation (BIR). To date, the North Texas-TBIMS has enrolled 100 patients into the national database with 62 patients receiving acute care at PHHS and 38 at BUMC, while 29 of these 100 patients received rehabilitative care at PHHS and 71 were patients at BIR. This collaborative system of care offers a unique opportunity within the Model System both from the patient and research perspective.



Rehabilitation Services at The University of Texas Southwestern Campus

There are two inpatient rehabilitation units on the UTSW campus, located at **Parkland Memorial Hospital (PMH)** and **Zale-Lipshy University Hospital (ZLUH)**. PMH has a 14-bed inpatient unit that specializes in the care of patients with brain injury and/or spinal cord injury. ZLUH has a 20-bed rehabilitation

unit that focuses on short stay programs to facilitate community re-entry for patients with moderate traumatic brain injury. Parkland's inpatient rehabilitation unit primarily serves the indigent patients of Dallas County thus playing a critical role in the treatment of this population because of the lack of Medicaid coverage for rehabilitation services in the state of Texas.

Acute Rehabilitation Services

Parkland's Physical Medicine and Rehabilitation (PM&R) department is recognized for its' excellence in quality care and services in treating patients with TBI. Physicians, physical therapists, occupational therapists, speech-language pathologists, recreational therapists, nurses, social workers and hydrotherapy specialists provide comprehensive interdisciplinary care in rehabilitation and research.

Long Term Follow-up

The patients discharged from Parkland's PM&R floor are followed at the **TBI Clinic** to assure continued medical management and successful integration into the community.

Rehabilitation Services at Baylor Institute for Rehabilitation

Baylor Institute for Rehabilitation (BIR) is the flagship hospital for rehabilitation services in the North Texas-TBIMS and is the primary receiving facility for rehabilitation of TBI patients in North Texas. It has a reputation for excellence in rehabilitation care and has been named eight times in *U.S. News and World Report* as one of the top rehabilitation hospitals in the U.S.A. BIR is a 116-bed, 112,000 square-foot free-standing rehabilitation hospital that specializes in comprehensive rehabilitation services for persons who have experienced brain injuries, spinal cord injuries, strokes, amputations and other orthopedic/neurological disorders. BIR serves 8 Level I / II trauma centers in North Texas and receives referrals from the surrounding states of Oklahoma, Arkansas, and Louisiana. The 80% discharge rate for TBI patients to the community substantially exceeds the regional and national averages. BIR was one of the first rehabilitation hospitals in the U.S. to utilize Care Maps (critical pathways) for determining length of stay and expected outcome in the rehabilitation of TBI patients. These care maps were developed at BIR in 1994, and presented at the TBI Model Systems meeting in Washington, D.C. in April of 1996.

Acute Rehabilitation Services

The Coma Management Program and associated process-oriented Care Maps are utilized for TBI patients who are slow to recover. Emphasis is placed on family education, medical interventions such as neurostimulants, and treatment protocols to reduce future complications. Of those patients admitted under the Coma Management Program over the past five years, greater than 80% emerged from coma and were able to enter the Active Traumatic



Baylor Institute for Rehabilitation

Brain Injury Rehabilitation Program while still an inpatient. **The Active TBI Rehabilitation Program** is designed for inpatients who can actively participate in therapies to achieve *functional* goals with outcome-oriented care maps ensuring interventions remain focused on timely completion of desired outcomes. The Active TBI Program provides multidisciplinary care to meet the varied medical and therapeutic needs of the patient during their inpatient stay.

Post-Acute Rehabilitation Services

BIR provides a comprehensive continuum of care with an array of specialized service programs offered to meet the individualized needs of the TBI patient. **The Day Neuro Rehabilitation Program** provides a six-hour daily program (Monday through Friday) of multidisciplinary treatment with the primary focus on cognitive rehabilitation for those patients desiring to resume school, work, or household endeavors. **The Real Life Rehabilitation Program** provides “in home” therapies specific for TBI patients. A multidisciplinary team, specially trained in establishing structure and routine for TBI survivors, guides and educates the patient and family as they transition to their home environment.

Long Term Follow-up

BIR provides a **TBI Follow-up Clinic** in which outpatients are seen by physician and therapy staff for assessment and treatment. The TBI follow up clinic has proven especially beneficial to those patients who return to communities outside of the Dallas-Ft Worth area by providing access to BIR and its staff as a life-long resource.

Joint Community Programs

Community Partners is a specialized community based program initiated by BIR in collaboration with the Speech/Language Pathology program at The University of Texas at Dallas in January of 2002. It is designed as a long-term intervention opportunity for TBI survivors who have completed the “rehabilitation phase” of their recovery. It is conducted two days a week and focuses on socialization, recreation, volunteerism, psychosocial skills, and

counseling. **Mountain High Camp** was one of the first “TBI Camps” in the nation and has been co-sponsored by BIR each August for the past eleven years in Red River, New Mexico. This five-day camp was created for young adult survivors of TBI. Many campers and families cite the building of self-esteem and independence as rewards of this camp experience and return year after year for this unique opportunity. In 2004, 175 TBI survivors and counselors, supported by BIR staff, participated in this camp.

Patient and family education

On admission to the TBI Rehabilitation Program, families of TBI survivors receive a “**TBI Family Notebook**” authored by the BIR TBI Team. It contains pertinent information written at a basic, easy-to-read level about the pathophysiology of TBI, common medical complications of TBI, and the process of rehabilitation and recovery. The “**Learning Lab**” and “**TBI Library**” are available to patients and families both in the inpatient and the outpatient setting. The learning lab contains didactic software programs concerning TBI and provides access to informational web sites that address TBI. The resource library provides numerous books on TBI, “family guides”, and literature authored by TBI survivors and their family members.

Advocacy/ Community Service

Members of the North Texas TBIMS have been actively involved in community and advocacy roles. BIR collaborated with Brain Net (the North Texas Brain Injury Resource and Network, Inc.), the Greater Dallas Brain Injury Collaborative, the Brain Injury Association of Texas, and the Brain Injury Association of Dallas to author and accomplish passage of Texas House Bill 1676 in 2001. This law prohibits “blanket exclusion” of cognitive rehabilitation services from medical insurance policies in the state of Texas. Ramon Diaz-Arrastia, M.D., Ph.D., the Project Director of the North Texas-TBIMS, served as Chair of the Professional Advisory Board of the Dallas Epilepsy Association 2000-2002. Mary Carlile, M.D., Medical Director of TBI Services at BIR, served as Chair of the Texas Traumatic Brain Injury Advisory Council (TTBIAC) for three years during the initial Texas Planning Grant of the Health Resources and Services Administration (HRSA). As a result of the work by TTBIAC, in 2003, the Texas legislature established a permanent TBI Advisory Council to assist the state in developing appropriate supports and services for TBI survivors. Dr. Carlile has continued to serve on the education committee of this council under a subsequent HRSA Implementation Grant and under the current HRSA Post Demonstration Grant. Under the current Post Demonstration Grant she, along with other members of the education committee, will provide education to the operators of Texas’ Information and Referral Network “211” concerning the special problems and needs of traumatic brain injury survivors. This training will also be provided to the “Promotoras” of the Rio Grande Valley who facilitate health care access for the Spanish speaking population of that region.

Collaborative Modular Projects

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Table 1. Comparison of Traditional vs. Modular Database Research in the TBIMS

	Traditional Database Research	Modular Research
Research topics:	Topics represented in existing NDB data elements	Topics selected by one of 5 Special Interest Groups; not limited to existing data elements
Type of design/ data collection:	Retrospective	Prospective, hypothesis-driven
Sample size:	Available participants in database	As needed based on power calculations
Contribution of individual centers:	All centers contribute all data, and the same data	Data are specific to project, and collected only by participating centers
Time frame:	Open-ended	Determined <i>a priori</i> by sample size needed and number of centers participating
Peer review:	None, although any TBIMS colleague may comment on project design	Brief, standardized review by 2-3 TBIMS colleagues not involved in project

As shown in the Table, one difference is that the new modular projects are peer reviewed, albeit informally. In 2003, the TBIMS Research Committee developed a process by which each of the new projects would be reviewed by 2-3 Committee members who were not involved in developing the project. Suggestions from the peer review were compiled in writing and fed back to the collaborating group prior to the scheduled start of data collection.

Research Topics for the Module Projects

As the concept of modular research was being discussed, it was also important to develop an organized way of selecting the first projects that would be completed using the new model. In December, 2002, the TBIMS Project Directors brainstormed a list of areas and topics of high importance for TBI research. Directors then sorted the topics into five broad areas, each of which became the focus of a Special Interest Group (SIG) charged with designing a research module. The five SIGs of the TBIMS are concerned with *Health, Cognitive Function, Psychological/ Emotional Function, Societal Participation, and Treatment*.

In 2003, each of these SIGs chose and began to develop its first modular research project. The result is five new collaborative research studies, all of which are now underway. Like the SIGs themselves, the projects reflect a variety of levels of analysis, from health and function to societal participation, and they examine both the outcomes of TBI and the treatment process in TBI rehabilitation. The design of the projects and all peer reviews were completed by the Spring of 2004, with data collection begun shortly thereafter. The five projects are described briefly below.

Health SIG: A prospective observational study of screening and prophylaxis for deep vein thrombosis in survivors of TBI during inpatient rehabilitation. Principal Investigator: Mary Carlile, MD. Lead Center: North Texas TBIMS, Dallas, TX.

This project capitalizes on the multi-center infrastructure of the TBIMS to study a condition that although important, occurs at a

relatively low rate: deep vein thrombosis (DVT). During acute rehabilitation, TBI patients often have cumulative risk factors for DVT. Morbidity and mortality associated with DVT includes pulmonary embolism (PE) as a particularly ominous complication. This study is a prospective observational study to determine the efficacy and cost effectiveness of DVT prevention and management methods. The project addresses several questions concerning effective screening, prophylaxis, and treatment methods for DVT in the rehabilitation setting. It is estimated that 2,000 subjects will be enrolled over 3.5 years at 10 participating centers. It is hoped that the study may provide a basis for guidelines as to screening and prophylaxis of DVT during inpatient rehabilitation after TBI.

Cognitive Function SIG: Feasibility and utility of a brief neuropsychological test battery for use during acute inpatient rehabilitation after TBI. Principal Investigator: Kathleen Kalmar, PhD. Lead Center: JFK-Johnson Rehabilitation Institute TBIMS, Edison, NJ.

Early neuropsychological test performance has been shown to be a powerful predictor of later outcome of TBI. This investigation seeks to show that: (1) the majority of patients admitted to the acute rehabilitation setting at one month after TBI will be able to complete a brief battery of formal neuropsychological tests in 75 minutes or less; (2) severity of cognitive impairment will be significantly correlated with measures of initial injury severity and degree of functional disability at one year post TBI; and (3) a Cognitive Severity Impairment index, to be developed as part of the project, will make a unique prediction to total length of stay and hospital charges relative to other known predictors. The project uses a battery of tests in widespread clinical use to measure attention, learning and memory, psychomotor speed, and executive function. The tests are administered at a standard interval post TBI rather than at the termination of PTA (as in some previous studies), to minimize the confounding of test results with injury severity. Formal data collection was started in July, 2004 at 7 participating centers.

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Collaborative Modular Projects

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Psychological/ Emotional Function SIG: Family members' and caregivers' emotional well-being. Principal Investigator: Jeffrey Kreutzer, PhD. Lead Center: Virginia Commonwealth TBIMS, Richmond, VA.

It is well known that family members and other caregivers are emotionally affected by TBI, and that they have a potentially invaluable role in rehabilitation and long-term care. The purpose of this project is to study caregivers' emotional well-being and life satisfaction as related to available supports, as well as survivors' injury severity and level of functioning. Specific goals include exploring whether level of social support moderates the relationship between well-being and survivor characteristics; and describing any differences in well-being among spouses, parents, and non-parent/ non-spouse significant others. Data collection, which for this project is focused on the caregiver rather than the survivor of TBI, is underway at 5 collaborating centers.

Participation SIG: Development of the Participation Assessment with Recombined Tools (PART). Principal Investigator: Gale Whiteneck, PhD. Lead Center: Rocky Mountain Regional TBIMS, Englewood, CO.

There is no general agreement in the field regarding a reliable and valid objective measure of community participation after TBI. The developers of four prominent and promising participation measures who are also TBIMS Project Directors have agreed to combine their instruments to form an item pool, from which a new and improved measure of participation (the PART) might emerge. The instruments are (1) the Craig Handicap Assessment and Reporting Technique Short Form (CHART-SF), (2) the Community Integration Questionnaire Version 2 (CIQ-2), (3) the Participation Objective-Participation Subjective (PO-PS) section of the Living Life After TBI (LLATBI), and (4) the Mayo-Portland Participation Index (MP2I). The items from these measures were recombined into a single tool, removing the most redundant items and re-ordering items for ease of administration. Data collectors at 8 collaborating centers were trained on the use of the Computer

Assisted Telephone Interview (CATI) system and database. As of September, 2004, the PART has been administered to almost 200 persons with TBI at the 1st, 2nd, 5th, 10th, or 15th anniversary of injury. At N = 400, Rasch and factor analytic techniques will be used to streamline and refine the PART from its current 78-item form to a shorter instrument. In a future phase, questions about the subjective components of participation will be added.

Treatment SIG: Characterizing and testing the relative efficacy of vocational rehabilitation interventions after TBI - Phase 1: Variations in vocational treatments across the TBIMS. Principal Investigator: Tessa Hart, PhD. Lead Center: Moss TBIMS, Philadelphia, PA.

The ability to work is important to many persons with TBI, but remains a goal that is very difficult to attain. It is important to learn more about what kinds of vocational treatment are most effective, when, and for whom. One obstacle to studying effectiveness is that there is no standard way to conceptualize and measure different components and models of treatment. This project seeks to (1) define and measure vocational treatments in a systematic way; (2) assess the range of vocational services offered across the TBIMS; and (3) use the accumulated data to develop feasible research hypotheses about the efficacy of vocational services. For this phase of the project, a collaborative group of Project Directors from 6 TBIMS centers developed a detailed survey that defines models, components, and intensities of vocational services. Data are collected by administering the survey over the phone, in semi-structured interview format, to the director of vocational services (or similar staff member) in each TBIMS. Both quantitative and qualitative data on the types of vocational services, as well as variations in services across the TBIMS centers, will be used to develop testable hypotheses for a second study phase: either an observational study comparing programs that differ along specified dimensions, or an experimental study comparing treatment approaches in a randomized controlled trial.

North Texas Traumatic Brain Injury Model System

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The North Texas TBIMS Consumer Advisory Council

The North Texas TBIMS Consumer Advisory Council is comprised of persons who represent the ethnic and cultural diversity of the North Texas Region and who are survivors of TBI, family members of survivors of TBI, and providers of services essential to the independence of persons with TBI. The council was organized in 2002 to ensure that clinical and research efforts of the North Texas-TBIMS are responsive to the needs of consumers. The council has helped guide the selection of research projects of the North Texas-TBIMS based on the potential of each study to improve outcomes following TBI.

Ongoing Research and Activities

The collaborating institutions of the North Texas TBIMS are committed to improving outcomes and delivery of supports and services to survivors of TBI. Through cutting edge research, innovative models of care, and continued advocacy, they will impact the lives of survivors of TBI in Texas and the nation. The following three projects were initiated by the North Texas-TBIMS.

Genetic Factors in Outcome after Traumatic Brain Injury

Ramon Diaz-Arrastia, M.D., Ph.D., Associate Professor of Neurology and North Texas- TBIMS Project Director, serves as Principal Investigator for this study which seeks to identify genetic polymorphisms that are associated with functional outcome after TBI. Recently, the possibility that genetic factors may influence functional outcome after TBI has been supported by the finding from several independent groups that inheritance of the APOE-e4

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Database Update

Scott Millis, Ph.D., Associate Director, TBI National Data Center

Ken Wood, Manager, TBI National Data Center

Incidence & Prevalence: Traumatic brain injuries contribute to a substantial number of deaths and cases of permanent disability annually. Each year in the United States, an estimated 1.4 million people sustain a TBI. Of those, 230,000 are hospitalized and survive, which is more than 20 times the number of hospitalizations for spinal cord injury, another key disabling injury. In addition, 50,000 people die from a TBI and 80,000 to 90,000 people experience the onset of long-term or lifelong disability associated with a TBI. At least 5.3 million Americans - 2% of the U. S. population - currently live with disabilities resulting from TBI.

The Traumatic Brain Injury Model System Database has been in existence since 1988. Since its inception, 21 federal-ly-funded TBI Model Systems of Care have contributed data to the National TBI Database. As of December 2004, the database contained information on 5044 persons with traumatic brain injuries. All the remaining statistics on this sheet are derived from this database or from collaborative studies conducted by the Model Systems.

Age at Injury: We have found an increase in the average age at time of injury. Prior to 1997, the mean age was 35.6 years. After that period, the mean age was 38.3 years. This difference is statistically significant ($t = 4.457$, $p = .0001$) and may reflect the fact that the median age of the general population of the United States has increased by approximately 8 years since the mid-1970s. Alternative explanations for the observed trend toward older age at injury include changes in either referral patterns to model systems, the locations of model systems, survival rates of older persons at the scene of the accident, or age-specific incidence rates.

Gender: Over the life of the Model Systems, men have consistently composed about three quarters of the database.

Ethnicity: Among persons injured between 1988 and 1996, 49.2% were Caucasian, 38.2.1% were African-American, 8.1% were Hispanic, and 2.3% were from other racial/ethnic groups. However, among those injured since 1997, 68.8% are Caucasian, 20.3% are African American, 7% are Hispanic, and 2.7% are Asian/Pacific Islander. This change in the ethnicity mix reflects modifications in sampling. In 1998, there was an increase in the number of Model System centers and a subsequent expansion in the diversity of persons sampled.

Etiology: Since 1997, motor vehicle crashes accounted for 48.3% of Model System cases. The next most common cause of TBI is falls (18.5%). Prior to 1997, the second most common cause of TBI in the database was blunt assaults (22.2%), which declined to 7.9% in the period of 1997-2004. During the former period, the Model Systems recruited persons with brain injuries from predominantly urban settings.

Injury Severity: Our sample continues to be characterized by severe brain injuries. Over 50% had Glasgow Coma Scale scores ranging from 3 to 8, were intubated, or were in chemical coma. Of the sample, 75% had Abbreviated Injury Scale (AIS) scores ranging from 4 to 6, with a median of 4 (severe). This level of severity has remained relatively consistent over time. There was no significant difference in AIS pre-1997 versus 1997-2004.

Occupational Status: More than half (63%) of those persons with TBI admitted to a Model System reported being employed at the time of their injury. By post-injury year 10, only 31% of persons in our sample were employed. Rate of pre-injury unemployment was 15%.

Residence: The overwhelming majority of persons with TBI in the Model System (98%) are sent to a private, noninstitutional residence (in most cases their homes before injury)

Marital Status: At the time of injury, 31% of persons with TBI in our sample were married. The proportion of sample that is married remains at about one-third at follow-up.

Length of Stay: Not surprisingly, average days hospitalized in the acute care unit for those who enter a Model System immediately following injury has declined from 23.3 days in the period 1988-1996 to 20.1 days for the period 1997-2004. This was a statistically significant decline ($t = 4.58$, $p = .0001$). A similar downward trend was noted for days in the rehabilitation, from 38.4 to 26.4 days. When focusing on more recent history, we found a similar trend in statistically significant declines in both acute care and rehabilitation lengths of stay (LOS). Mean acute length of stay was 20.9 days for the period 1998-2000 versus 19.6 days for the period 2001-2004. Rehabilitation LOS declined from 28.4 days to 24.9 days for the same periods.

Database Update

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PRE-INJURY STATUS and INJURY DATA

Enrollment: July 2003 - June 2004 = 738 Total = 5044

Variable	Last year	Total	Variable	Last year	Total
PREINJURY STATUS			MEDICAL		
Age (mean)	39	38	<i>Cause of injury</i>		
Gender (% male)	72	74	Motor vehicle (%)	46	46
<i>Marital status</i>			Violence (%)	11	15
Single, never married (%)	48	49	Sports/recreation (%)	1	1
Married/common law (%)	32	31	Pedestrian (%)	7	8
Divorced/separated/widowed (%)	19	20	Falls/flying objects (%)	23	19
<i>Living status</i>			GCS total (mean)	11	11
Alone (%)	19	18	PTA (mean # of days)	24	28
w/ Related adults (%)	65	65	LOS – acute hospital (mean)	20	21
w/ Unrelated adults (%)	16	17	LOS – inpatient rehab (mean)	24	29
Education Years(median)	12	12	LOS – acute & rehab combined (mean)	44	50
<i>Employment status</i>			Charges – acute hospital (mean)	185,905	124,907
Full time student (%)	7	8	Charges – inpatient rehab (mean)	60,689	47,485
Employed (%)	59	63	Charges – combined (mean)	246,594	172,392
Unemployed (%)	13	15			
Retired (%)	16	10	FUNCTIONAL OUTCOMES		
Any drug use (%)	23	26	DRS at rehab admission (mean)	13	12
Any alcohol use (%)	65	61	DRS at rehab discharge (mean)	6	6
			FIM at rehab admission (mean)	50	52
			FIM at rehab discharge (mean)	92	91
			FIM gain (mean)	42	39
			FIM gain per day (mean)	1.7	1.3
			Residence at discharge (% to private residence)	83	85

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Database Update

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CONDITION AT FOLLOW-UP

Variable	1yr		2yr		5yr		10yr	
	year	total	year	total	year	total	year	total
number of cases:	n=486	n=3942	n=430	n=2767	n=210	n=1149	n=44	n=379
Deceased (%)	2.3	1.7	1.9	2.1	1.9	2.3	9.0	3.9
DRS (mean)	2.9	2.7	2.4	2.5	2.6	2.5	2.5	2.4
FIM (mean)	114	114	116	116	116	116	116	116
GOSE (mean)	5.6	5.5	5.9	5.7	5.8	5.7	5.4	5.5
<i>Marital status</i>								
Single, never married (%)	47	48	47	48	41	45	50	46
Married/common law (%)	31	30	30	30	32	27	25	27
<i>Living status</i>								
Alone (%)	13	11	17	15	19	19	7	17
w/ Related adults (%)	81	82	77	79	73	73	89	76
w/ Unrelated adults (%)	6	7	6	6	8	8	5	6
Residence (% in private residence)	92	91	93	90	91	89	95	90
<i>Employment status</i>								
Full time student (%)	5	5	7	5	2	2	0	0
Employed (%)	24	27	32	31	33	33	23	31
Unemployed (%)	33	40	24	33	21	31	25	30
Retired (%)	29	17	30	19	35	21	41	26
Drug use (%)	9	12	11	13	10	12	7	16
Alcohol use (%)	28	32	38	38	41	42	36	41
Drives vehicle (%)	41	41	50	48	49	48	40	50
Satisfaction with life (mean)	21	20	22	21	21	21	20	21

North Texas Traumatic Brain Injury Model System

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allele increases the risk of poor neurologic recovery. It is likely that polymorphisms in other genes also influence the response of neural tissue to injury or the extent of recovery and repair.

Evaluation of Cognitive Impairment after Traumatic Brain Injury Using Functional MRI (fMRI)

Zerrin Yetkin, M.D., Assistant Professor of Neuroradiology at UTSW, is the Principal Investigator for this study that seeks to use functional magnetic resonance imaging (fMRI) to examine possible changes in brain activation acutely and over the course of recovery from TBI and its association with outcome.

A Prospective Observational Study of Screening and Prophylaxis for Deep Vein Thrombosis in Survivors of Traumatic Brain Injury during Inpatient Rehabilitation

Mary Carlile, M.D., Medical Director, TBI Services BIR and Co-Project Director of the North Texas- TBIMS, is Principal Investigator of this multi-center Health Module study of the TBI

Model System. The development of deep venous thrombosis (DVT) is a significant complication that increases morbidity and mortality during the period of acute rehabilitation for TBI. Pulmonary embolism (PE) is one of the most ominous, and frequently life-threatening, complications that occur during TBI rehabilitation. This study will provide evidence to answer pivotal questions concerning DVT and PE prevention in the rehabilitation setting. From the 11 participating sites, almost 200 patients (including 90 from the North Texas-TBIMS) have been enrolled in the DVT study protocol.

The North Texas-TBIMS has benefited from the affiliation of two of the most respected tertiary care medical and rehabilitation centers in north Texas; institutions that emphasize both quality research and clinical care. The joining of these hospital systems as collaborators in the North Texas TBIMS presents a distinct opportunity to meld the resources of public and private institutions. Through this cooperative effort, researchers are able to create and implement innovative research ideas to advance the treatment and improve the outcomes of TBI survivors.

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