The evolution of model systems of care in traumatic brain injury

J. Paul Thomas, PhD
Director
Medical Sciences Programs
National Institute on Disability and Rehabilitation Research
US Department of Education
Washington, DC

Based on the referral experience of the acute care components of several federally designated model spinal cord injury (SCI) systems, the problem of traumatic brain injury (TBI) became identified to the federal Rehabilitation Services Administration (RSA) in 1975 to 1976. The model SCI systems were developed and supported as research and demonstration models by the RSA for a dedicated, coordinated service delivery system addressing a specific type of neurologic trauma (i.e., spinal cord injury).

MODEL SCI SYSTEMS

The model SCI systems, a significant innovation in rehabilitation services delivery, cover all aspects of care: from emergency evacuation and advanced life support at the accident scene, through intensive care, comprehensive physical and psychosocial rehabilitation, and long-term community follow-up. By 1976, there were seven model SCI systems established, all with a tightly coordinated, effective,
field-based emergency medical and in-hospital traumatology capability. It was this first response-traumatology network that identified neurological trauma of all kinds, including brain trauma. While a coordinated system of rehabilitation care existed for SCI, brain injury victims were not able to access similar services and programs, perhaps because very few of these programs existed. Their clinical course was uncertain, and they tended to remain in acute care settings without purposeful movement toward optimal rehabilitation goals.

A simplistic assessment of brain injury outcomes readily indicated that these patients' rehabilitation needs were not being met. Frequently, brain injury patients were discharged from acute care settings to home, long-term nursing facilities, or psychiatric programs. Most often, behavioral, cognitive, and other dysfunction produced unbearable family and community stresses.

After a detailed research planning effort that incorporated nonfederal and federal experts, a request for research proposals in TBI was announced in the Federal Register in fiscal year 1978. This announcement called for the support of two companion research and demonstration projects to work collaboratively and individually on a common mission. The common objectives included

- study of the clinical course of brain injury;
- identification and quantification of significant rehabilitation problems and gaps in service delivery based on the clinical course; and
- proposal of an appropriate service delivery model for TBI.

The first TBI projects were the first scientific investigations for the new National Institute of Handicapped Research (NIHR), more recently renamed the National Institute on Disability and Rehabilitation Research (NIDRR). Four-year awards were made to New York University Medical Center with Sheldon Berrol, MD, as project director. Four years later these productive research projects would generate definitive final reports that remain useful today.

Armed with the two definitive final reports as research guides, the growing interest and enthusiasm for new knowledge about brain injury in the rehabilitation field, and the support and advocacy of the National Head Injury Foundation, the NIHR awarded four university-based rehabilitation research and training centers in TBI in 1983. These four research centers, which provided a significant influence on program development and acquisition of new research information, were located at New York University, Emory University, Northwestern University-Rehabilitation Institute of Chicago, and the University of Washington. More than 75 projects were conducted by the four centers, providing a major thrust in TBI research.

More recently, four new TBI-focused research and training centers were announced in fiscal year 1987. These university-based research centers will investigate all aspects of brain injury and programs will focus on moderate injury, severe injury and prolonged coma, and community reintegration issues.

The institutions receiving research and training center designation for fiscal year 1988 include

- New York University Medical Center (moderate injury), Leonard Diller, PhD, Project Director;
- Medical College of Virginia (severe injury), Henry Stonnington, MD, Project Director;
- State University of New York at Buffalo (community reintegration), John Noble, PhD, Project Director; and
- University of Washington (moderate injury), Justus F. Lehmann, MD, Project Director.

In 1984, under the dynamic and capable leadership of Douglas A. Fenderson, PhD, the
NIHR developed two new research initiatives that have stimulated TBI research: the Field Initiated Research Program and the Switzer Fellowship Program. Both support the achievement of new research knowledge and enhancement of research careers in rehabilitation research. Since announcement of the Field Initiated Research and Fellowship Programs, a significant expansion of research funding for TBI has occurred. By fiscal year 1987, eight field-initiated projects and five Switzer distinguished fellows in TBI research were funded.

While research projects and other resources were evolving, an organizational strategy had not been developed to allow controlled growth, rapid dissemination of outcomes, joint future program expansion, federal interagency coordination, and the conceptualization and implementation of a service delivery model for TBI. In April 1986, before the spring meeting of the National Head Injury Foundation, Assistant Secretary of Education Madeleine Will announced a major programmatic initiative on TBI. This initiative was the result of rapid but disorganized development of programs, resources, and new knowledge acquisition in the field of brain injury rehabilitation. The TBI initiative addressed several important areas of brain injury rehabilitation including organized planning and program development, new fiscal resources for additional research, development of model comprehensive service delivery demonstrations, coordination of federal research efforts, and public education and prevention programs. For purposes of this presentation, emphasis will be given to the model TBI systems program.

MODEL TBI SYSTEM DEMONSTRATIONS

Based on an NIDRR-directed research priority, five new national demonstration projects were awarded and initiated in fiscal year 1987. The models focus on the comprehensive delivery of services from point of injury through intensive neurological care, comprehensive physical and psychosocial rehabilitation, and community reintegration and long-term follow-up. A national TBI database will be established as part of the research and demonstration activity.

Five projects were awarded at an annual cost of $1.5 million to the following sites:
- Mt Sinai Medical Center, New York. Kristjan T. Ragnarsson, MD, Project Director;
- Wayne State Medical Center, Detroit. Fred Lamb, MD, Project Director;
- Medical College of Virginia, Richmond, Virginia. Jeffrey Kreutzer, PhD, Project Director;
- The Institute for Rehabilitation and Research, Houston. Catherine Bontke, MD, Project Director; and
- Santa Clara Valley Medical Center, San Jose, California. Jeffrey Englander, MD, Project Director.

The objectives of the model TBI systems include the following:
- Demonstrate and evaluate the cost-benefit and service delivery outcomes of a comprehensive service delivery system for individuals with TBI.
- Establish a research program to develop a new database and conduct innovative analyses of TBI research data.
- Demonstrate and evaluate the development and application of improved and innovative methods essential to the care and rehabilitation of individuals with TBI.
- Participate in national studies of the brain injury model system concept by contributing to a national TBI database as prescribed by the Secretary of Education.

The comprehensive continuum of treatment or systems approach to spinal cord injury care exemplifies the rehabilitation effectiveness and cost containment that categorical care makes feasible. As cost-effectiveness and clinical outcomes have been demonstrated, support for the system-of-care concept within
the scientific community has increased and many of the principles of the approach have been adopted in the management of other complex disorders such as TBI. The improvements (i.e., reduced length of hospital stay, reduced complication rates, increased cost-effectiveness, and increased social and vocational productivity) that may be achieved by expanding an organized treatment plan into a model systems approach for TBI should not be ignored. The basis for a model systems approach to care for catastrophic injury has been established. The major elements of a TBI service delivery system are established and operating in many sites. What is needed now is to go one step further and implement the same systems approach currently being used in the treatment of SCI and to develop a realistic, statistically powerful database to document and evaluate the collective national experience for TBI.

The following principles of the model SCI system are applicable to TBI.

Service delivery

- A modified system for TBI can work in a humanitarian and cost-efficient manner by streamlining care, preventing secondary complications, and maximizing rehabilitation potential.
- Most of the five service components are appropriate and relevant: emergency medical services; intensive-acute medical care; comprehensive, coordinated rehabilitation; psychosocial and vocational preparation; and long-term community follow-up.
- Many of these major elements of a TBI service delivery system already are established and operating in numerous sites.
- A critical mass of patients is essential in building expertise.
- Fiscal and clinical accountability of professional services can be demonstrated to payers.
- Physicians, allied health professionals, administrators, and families can plan programs together in a professional, organized, and outcome-oriented manner.
- Psychosocial and vocationally oriented services must begin early in the acute and comprehensive rehabilitation stages.
- Aggressive follow-up services are essential for maintaining gains made during in-hospital rehabilitation.
- The service system is a dynamic, continually changing phenomenon that requires constant attention to maintain linkages and optimal services.

Research and evaluation

- A coordinated, standardized data collection plan is essential to measure service delivery, clinical outcomes, and to provide a statistical basis for clinical decision making.
- A data plan can legitimately include a registry component to evaluate local epidemiologic trends and effectiveness of referral and primary prevention activities.
- Collaborative or shared research can generate meaningful, definitive data much faster than single-site research.
- A research-oriented philosophy may stimulate a "questioning" mode of service delivery, which can ultimately enhance quality of care and clinical outcomes.

Education and training

- Neurological trauma and rehabilitation lends itself to a medical teaching model because of both multispecialty and extensive body system involvement.
- A system builds a critical mass of specialty and allied health expertise.
- A system becomes a demonstration showcase for the innovation of new programs and services in other localities.
• The system resources and facilities are a focal point for primary prevention and public education.

Advocacy

• The system facilities, personnel, and relationships provide the resources for purposeful and effective public advocacy for disability-oriented programs and services.

As rehabilitation professionals we are obligated to utilize new research knowledge in a purposeful and innovative manner. The model SCI systems experience has afforded many important implications for rehabilitation service delivery modeling for brain injury and other disabilities as well.

The rehabilitation management of TBI victims is a complex, multidisciplinary challenge. All of their acute care and rehabilitation needs are probably best achieved in a coordinated system of services. These five new research and demonstration models will provide significant leadership and resources in meeting the challenges of the future.