NIH Consensus Statement

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Rehabilitation of Persons with Traumatic Brain Injury

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This statement reflects the panel's assessment of medical knowledge available at the time the statement was written. Thus, it provides a "snapshot in time" of the state of knowledge on the conference topic. When reading the statement, keep in mind that new knowledge is inevitably accumulating through medical research.

National Institutes Of Health/Foundation for Advanced Education in the Sciences
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Disclosure Statement

All of the panelists who participated in this conference and contributed to the writing of this consensus statement were identified as having no financial or scientific conflict of interest, and all signed conflict of interest forms attesting to this fact. Unlike the expert speakers who present scientific data at the conference, the individuals invited to participate on NIH consensus panels are selected specifically because they are not professionally identified with advocacy positions with respect to the conference topic or with research that could be used to answer any of the conference questions.

Abstract

Objective

The objective of this NIH Consensus Statement is to inform the biomedical research and clinical practice communities of the results of the NIH Consensus Development Conference on Rehabilitation of Persons with Traumatic Brain Injury. The statement provides state-of-the-art information regarding effective rehabilitation measures for persons who have suffered a traumatic brain injury (TBI) and presents the conclusions and recommendations of the consensus panel regarding these issues. In addition, the statement identifies those areas that deserve further investigation. Upon completion of this educational activity, the reader should possess a clear working clinical knowledge of the state of the art regarding this topic. The target audience for this statement includes, but is not limited to, pediatricians, family practitioners, internists, neurologists, physiatrists, psychologists, and behavioral medicine specialists.

Participants

Participants were a non-Federal, nonadvocate, 16-member panel representing the fields of neuropsychology, neurology, psychiatry, behavioral medicine, family medicine, pediatrics, physical medicine and rehabilitation, speech and hearing, occupational therapy, nursing, epidemiology, biostatistics and the public. In addition, 23 experts from these same fields presented data to the panel and a conference audience of 883.

Evidence

The literature was searched through Medline and an extensive bibliography of references was provided to the panel and the conference audience. Experts prepared abstracts with relevant citations from the literature. A compendium of evidence was prepared by the panel which included a contribution from a patient with TBI, a report from an

Evidence Based Practice Center of the Agency for Health Care Policy and Research, and a report from the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention. Scientific evidence was given precedence over clinical anecdotal experience.

Consensus Process

The panel, answering predefined questions, developed their conclusions based on the scientific evidence presented in open forum and the scientific literature. The panel composed a draft statement that was read in its entirety and circulated to the experts and the audience for comment. Thereafter, the panel resolved conflicting recommendations and released a revised statement at the end of the conference. The panel finalized the revisions within a few weeks after the conference. The draft statement was made available on the World Wide Web immediately following its release at the conference and was updated with the panel's final revisions.

Conclusions

Traumatic Brain Injury (TBI) results principally from vehicular incidents, falls, acts of violence, and sports injuries, and is more than twice as likely in males as in females. The estimated incidence rate is 100 per 100,000 persons with 52,000 annual deaths. The highest incidence is among persons 15 to 24 years of age and 75 years and older, with an additional less striking peak in incidence in children ages 5 and younger. Since TBI may result in lifelong impairment of an individual's physical, cognitive, and psychosocial functioning and prevalence is estimated to be 2.5 million to 6.5 million individuals, TBI is a disorder of major public health significance. Furthermore, mild TBI is significantly under diagnosed and the likely societal burden therefore even greater. Given the large toll of TBI and absence of a cure, prevention is of paramount importance. However, the focus of this conference was the evaluation of rehabilitative measures available for the cognitive and behavioral consequences of TBI.

Although studies are relatively limited, available evidence supports the use of certain cognitive and behavioral rehabilitation strategies for individuals with TBI. This research needs to be replicated in larger, more definitive clinical trials. Well-designed and controlled studies using innovative methods are needed to evaluate the benefits of different rehabilitation interventions. Increased understanding of the mechanisms of TBI and recovery hold promise for new treatments. Thus, funding for research on TBI needs to be increased. Persons with TBI, their families, and significant others are integral to the design and implementation of the rehabilitation process and research. Consequently, rehabilitation services, matched to the needs of persons with TBI, and community-based nonmedical services are required to optimize outcomes over the course of recovery. Public and private funding for rehabilitation of persons with TBI must be adequate to meet these acute and long-term needs, especially in consideration of the current healthcare environment where access to these treatments may be jeopardized by changes in payment methods for private insurance and public programs.

Introduction

Traumatic brain injury (TBI), broadly defined as brain injury from externally inflicted trauma, may result in significant impairment of an individual's physical, cognitive, and psychosocial functioning. In the United States, an estimated 1.5 to 2 million people incur TBI each year, principally as a result of vehicular incidents, falls, acts of violence, and sports accidents. The number of people surviving TBI with impairment has increased significantly in recent years, which is attributed to faster and more effective emergency care, quicker and safer transportation to specialized treatment facilities, and advances in acute medical management. TBI affects people of all ages and is the leading cause of long-term disability among children and young adults.

Each year, approximately 70,000 to 90,000 individuals incur a TBI resulting in a long-term, substantial loss of functioning. The consequences of TBI include a dramatic change in the individual's life-course, profound disruption of the family, enormous loss of income or earning potential, and large expenses over a lifetime. There are approximately 300,000 hospital admissions annually for persons with mild or moderate TBI, and an additional unknown number of traumatic brain injuries (TBIs) that are not diagnosed but may result in long-term disability.

Although TBI may result in physical impairment, the more problematic consequences involve the individual's cognition, emotional functioning, and behavior. These impact interpersonal relationships, school, and work. Cognitive-behavioral remediation, pharmacologic management, assistive technology, environmental manipulation, education, and counseling are among currently used treatments of these sequelae. These treatments are provided in freestanding rehabilitation hospitals, rehabilitation departments in general hospitals, a variety of day treatment or residential programs, skilled nursing facilities, schools, the community, and the home.

The Traumatic Brain Injury Act of 1996 instructed the Secretary of Health and Human Services, acting through the Director of the National Center for Medical Rehabilitation Research within the National Institute of Child Health and Human Development, to conduct "a national consensus conference on managing traumatic brain injury and related rehabilitation concerns." The NIH organized a 2½-day conference to evaluate the scientific data concerning rehabilitation practices for persons with TBI. Particular emphasis was placed on rehabilitation of cognitive, behavioral, and psychosocial difficulties associated with mild, moderate, and severe TBI. The conference brought together national and international biomedical researchers and clinicians, as well as persons with TBI and their families.

On the second day of the conference, 1½ hours were allocated for brief oral presentations by individuals representing interested organizations regarding the conference issues and by persons wishing to present their own individual statements.

After 1½ days of presentations and audience discussion, an independent, non-Federal consensus panel chaired by Dr. Kristjan T. Ragnarsson, Professor and Chair, Department of Rehabilitation Medicine, Mount Sinai School of Medicine, weighed the scientific evidence and wrote a draft statement that was presented to the audience on the third day. The statement took into account the panel's year-long review of the scientific literature. The consensus statement addressed the following key questions:

- What is the epidemiology of traumatic brain injury in the United States, and what are its implications for rehabilitation?
- What are the consequences of traumatic brain injury in terms of pathophysiology, impairments, functional limitations, disabilities, societal limitations, and economic impact?

- What is known about mechanisms underlying functional recovery following TBI, and what are the implications for rehabilitation?
- What are the common therapeutic interventions for the cognitive and behavior sequelae of TBI, what is their scientific basis, and how effective are they?
- What are common models of comprehensive, coordinated, multidisciplinary rehabilitation for people with TBI, what is their scientific basis, and what is known about their short-term and long-term outcomes?
- Based on the answers to these questions, what can be recommended regarding rehabilitation practices for people with TBI?
- What research is needed to guide the rehabilitation of people with traumatic brain injury?

The lead organizations of this meeting were the National Institute of Child Health and Human Development and the NIH Office of Medical Applications of Research. The conference was also supported by the National Institute on Deafness and Other Communication Disorders, the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, the National Institute of Nursing Research, the Office of Alternative Medicine, and the Office of Research on Women's Health of the NIH; the Agency for Healthy Care Policy and Research; and the Centers for Disease Control and Prevention.

What Is the Epidemiology of Traumatic Brain Injury in the United States, and What Are Its Implications for Rehabilitation?

The epidemiology of TBI, including incidence, prevalence, etiology, and natural history, can guide our estimates of the demand for and range of required TBI rehabilitation services. Data from Centers for Disease Control and Prevention (CDC)-sponsored State surveillance projects report annual rates of TBI of 100 per 100,000 persons with 52,000 annual deaths. Prevalence estimates range from 2.5 million to 6.5 million individuals living with the consequences of TBI. These estimates, however, suffer from ascertainment bias since they are based exclusively on information about hospitalized patients and those who die before hospitalization.

It is important to separately address mild, moderate, and severe TBI. Until data are available beyond those based on hospitalized patients, it will not be possible to understand and study the full spectrum of the disease. The recent State surveillance systems directed in part by CDC have adopted common data collection and reporting methods, which provide good epidemiologic data about persons with TBI who are hospitalized or die. Newer methodologies to assess the epidemiology of mild TBI that does not result in hospitalization should be developed and its incidence and prevalence rigorously studied.

Existing data point to potential areas for prevention of TBI and design of rehabilitation programs. Males are more than twice as likely as females to experience TBI. The highest incidence is among persons 15 to 24 years of age and 75 years and older, with an additional less striking peak in incidence in children ages 5 and younger. Alcohol is reported to be associated with half of all TBI, either in the person causing the injury or in the person with the injury.

Approximately 50 percent of TBIs are the result of motor vehicle, bicycle, or pedestrian-vehicle incidents. Safety belts, air bags, infant and child car seats, as well as changes in speed limits, road design, and traffic control have reduced motor vehicle-related deaths and TBI. Additional preventive measures to reduce TBI caused by alcohol-related motor vehicle accidents should be developed and assessed.

Falls are the second most frequent cause of TBI among the frail elderly and the very young. Risk factors for falls among the elderly include alcohol, medication, and osteoporosis. Few preventive measures are in place for either the very young or the elderly; however, there have been some changes in the design of walkers, strollers, and shopping carts to help prevent falls among young children.

Violence-related incidents account for approximately 20 percent of TBI. These incidents are almost equally divided into firearm and non-firearm assaults. The highest incidence for TBI due to firearms is among people ages 15 to 24. This is also a high-risk age for non-firearm assaults. Programs to prevent street violence must be strengthened, especially through legislation to control use of handguns and to increase their safety.

Assault is also a major cause of TBI in the very young. Although unintentional injuries account for 75 percent of TBI in this age group, child abuse is also an issue. Shaken baby syndrome results specifically in TBI and spinal cord injury. Domestic violence affects children and adults of both genders.

Although sports- and recreation-related injuries account for 3 percent of hospitalized persons with TBI, approximately 90 percent of sports-related TBIs are mild and may go unreported, thus leading to the underestimate of the actual incidence rate of sports-related TBI. Sports-related TBI occurs most frequently among people ages 5 to 24 who have many decades of life ahead. Risk factors are poorly delineated. There is great promise for prevention of sports-related TBI.

Risk factors for these causes of TBI are rarely studied, leaving large gaps in the knowledge of appropriate prevention strategies and the association of those risk factors with etiologies and outcomes. In addition, etiologies and risk factors may affect the selection of rehabilitation strategies. For example, children with TBI secondary to child abuse or street violence may have limited options for community-based rehabilitation. Injuries related to alcohol or drug abuse often necessitate chemical dependency treatment in the rehabilitation process.

These epidemiologic profiles indicate that TBI is extremely heterogeneous. This is apparent in the distribution of TBI by age, gender, ethnicity, severity, and cause. Multiple rehabilitation strategies to accommodate these complexities are needed.

What Are the Consequences of Traumatic Brain Injury in Terms of Pathophysiology, Impairments, Functional Limitations, Disabilities, Societal Limitations, and Economic Impact?

Rarely are the consequences limited to one set of symptoms, clearly delineated impairments, or a disability that affects only one part of a person's life. Rather, the consequences of TBI often influence human functions along a continuum from altered physiological functions of cells through neurological and psychological impairments, to medical problems and disabilities that affect the individual with TBI, as well as the family, friends, community, and society in general. When other, more urgent medical problems are apparent at onset, mild TBI may be masked, even though it can result in impairments. In many cases, the consequences of TBI endure in original or altered forms across the lifespan, with new problems likely to occur as a result of new challenges and the aging process.

The neurological consequences of TBI are many and complex, occurring throughout the neural axis. Any sensory, motor, and autonomic function may be compromised. Most of these complications are apparent within the first days or months following injury, depending on the severity of initial trauma. Some long-term sequelae include a variety of movement disorders, seizures, headaches, ambient visual deficits, and sleep disorders. Non-neurological medical complications include, but are certainly not limited to, pulmonary, metabolic, nutritional, gastrointestinal, musculoskeletal, and dermatologic problems.

The cognitive consequences of TBI are similarly broad. All of these consequences can occur singly or in combinations and are variable in terms of their effects on individuals; furthermore, they change in severity and presentation over time. In combination, they produce a myriad of functional problems. Some of the most persistent problems include memory impairment and

difficulties in attention and concentration. Deficits in language use and visual perception are common, but often unrecognized. Frontal lobe functions, such as the executive skills of problem-solving, abstract reasoning, insight, judgment, planning, information processing, and organization, are vulnerable to TBI.

Common behavioral deficits include decreased ability to initiate responses, verbal and physical aggression, agitation, learning difficulties, shallow self-awareness, altered sexual functioning, impulsivity, and social disinhibition. Mood disorders, personality changes, altered emotional control, depression, and anxiety are also prevalent after TBI.

Social consequences of mild, moderate, and severe TBI are many and serious, including increased risk of suicide, divorce, chronic unemployment, economic strain, and substance abuse. These consequences are tragic to individuals and families and place additional burdens on social service agencies, law enforcement, and the courts. As individuals with TBI attempt to resume their usual daily activities, the environment places increasing demands on them, uncovering additional psychosocial consequences. For example, executive dysfunction may become obvious only in the workplace; behavioral changes affecting interpersonal relationships may appear after leaving inpatient care. Spiraling adverse consequences of TBI may become apparent not only for persons with TBI but also for their significant others. Family members report depression, social isolation, and anger. Overall family functioning and relationships are disrupted. Such consequences may continue and, in some instances, worsen with age.

Children with TBI have their own set of consequences. Interactions of physical, cognitive, and behavioral sequelae interfere with the task of new learning. The effect of early TBI may not become apparent until later in the child's development, although there is little explicit literature on

the developmental consequences of TBI in infants. There may be a poor fit between the needs of children with TBI and the typical school educational programs. Children with TBI also may have difficulties with peers due to cognitive processing, behavioral problems, or difficulty comprehending social cues. Parents are faced with significant parenting challenges, including coping with changed academic aspirations and family goals.

TBI in adolescents has been largely unstudied. It is unclear, therefore, whether the consequences they face are best described by the literature pertaining to adults or children.

The economic consequences of TBI are enormous. The annual cost of acute care and rehabilitation in the United States for new cases of TBI is estimated at $9 to $10 billion. Estimates for average lifetime cost of care for a person with severe TBI range from $600,000 to $1,875,000. These figures may grossly underestimate the economic burden of TBI to family and society because they do not include lost earnings, costs to social services systems, and the value of the time and foregone earnings of family members who care for persons with TBI.

Access to initial care and subsequent rehabilitation for persons with TBI may depend greatly on insurance coverage, health care personnel, family and community, geographic location, knowledge of available resources, and the ability to navigate the medical care and rehabilitation system successfully.

What Is Known About Mechanisms Underlying Functional Recovery Following TBI, and What Are the Implications for Rehabilitation?

TBI represents an evolving dynamic process that involves multiple interrelated physiological components that exert primary and secondary effects at the level of the individual nerve cell (neuron), the level of connected networks of such neurons (neural networks), and the level of human thought (cognition). Many damaging changes to the connections among neurons (axons) and to the neurons themselves have been described. These include chemical changes to the basic molecules of metabolism (especially calcium), to mechanisms of the human cellular response to injury, and to the quantities of certain molecules that can be dangerous in excess (oxygen free radicals, nitric oxide). A protein substance that is present in Alzheimer's disease (beta amyloid) also can be deposited in neurons. Communication molecules in the brain (neurotransmitters) have either excitatory or inhibitory effects. The most prevalent of these excitatory molecules are the amino acids glutamate and aspartate, which can occur in massive amounts following TBI, leading to overexcitation and ultimately the death of neurons. At the cognitive level, alterations in neural networks and neurotransmitter systems (especially ones involving the transmitters acetyl choline, dopamine, and serotonin) can affect cognition and behavior.

Although the pathophysiology of TBI is under intense investigation in animals, application of these findings to the understanding of neurobiological mechanisms underlying functional recovery in humans remains to be delineated. The relative importance of each mechanism to recovery potential at different stages after TBI remains unclear.

The basic mechanisms of injury and recovery have motivated the evaluation of experimental treatments in animals (e.g., protection of neurons from overexcitation or the effects of damaging molecules), whereas basic understanding of the capacity of neurons to grow and form connections with other

neurons (cellular plasticity) has motivated others. The injured brain does have some capacity to recover. Elements of neural plasticity include increases of chemicals that promote growth of neural connections (growth factors) and alterations in the number and nature of these connections through changes in neuron structure. Promising strategies in neuroplasticity include nerve growth factors, other mediators of growth, and tissue transplantation. Ultimately, gene therapy may be a way to deliver such growth factors to targeted locations. Interventions to improve neural network and cognitive function may involve particular types of experience and stimulation (e.g., complex environments), with experience-dependent changes demonstrable in the biology of neural connections, small blood vessels, and even the organization of brain layers.

The temporal course of recovery is probably lengthy (months to years), and the rate of recovery may vary over time. Recovery may incorporate particular substages that have unique pathophysiology. The temporal course may exhibit regional and functional differences. For example, at the cellular level, a particular type of cell death (apoptosis), which is normally present only during early brain development, may occur in different regions at different times, including many months following injury. At the neural network level, experience-dependent changes related to activity or learning have been demonstrated at various times after experimental brain damage in animals. Cognitive recovery proceeds in overlapping stages, with more marked improvements in particular skills occurring at different times. In addition, great variability in behavior is characteristic after TBI. Mechanisms currently used for reestablishing appropriate and adaptive behaviors in adults with TBI include learning, the development of supportive contexts, and environmental manipulations. These mechanisms focus not only on persons with TBI, but also on their families and the communities in which they live. Given the complexity of the recovery processes, treatment protocols likely will need to be carefully designed and systematically staged to introduce these potential therapeutic interventions consistent with the temporal sequence of pathophysiological and plastic events.

The gap between animal model studies of interventions and human clinical practice is particularly wide. Four reasons for this gap are (1) the differences between induced animal injury (e.g., fluid percussion injury) and human TBI, (2) the differences in severity of injury, (3) the timeframes of interventions for particular impairments, and (4) the presence of intolerable side effects. Furthermore, studies in animals are unable to address the complicated behavioral characteristics of human cognition after TBI. Successful study of brain/behavior relationships after TBI may depend on comparing cognitive domains (e.g., learning, attention, concentration, and memory) with biological processes, which can be studied only in humans.

Several conclusions from this review are possible. The time course of TBI is prolonged and, in some cases, lifelong. The neural and cognitive mechanisms of injury and recovery are myriad, complex, and interrelated. Different underlying mechanisms are active at different times during recovery; consequently, specific interventions might have beneficial effects at certain times and not others. Although certain rehabilitative interventions probably should be started immediately, others probably should be delayed to maximize effectiveness and minimize adverse effect.

What Are the Common Therapeutic Interventions for the Cognitive and Behavioral Sequelae of TBI, What Is Their Scientific Basis, and How Effective Are They?

The goals of cognitive and behavioral rehabilitation are to enhance the person's capacity to process and interpret information and to improve the person's ability to function in all aspects of family and community life. Restorative training focuses on improving a specific cognitive function, whereas compensatory training focuses on adapting to the presence of a cognitive deficit. Compensatory approaches may have restorative effects at certain times. Some cognitive rehabilitation programs rely on a single strategy (such as computer-assisted cognitive training), while others use an integrated or interdisciplinary approach. A single program can target either an isolated cognitive function or multiple functions concurrently.

Despite many descriptions of specific strategies, programs, and interventions, limited data on the effectiveness of cognitive rehabilitation programs are available because of heterogeneity of subjects, interventions, and outcomes studied. Outcome measures present a special problem, since some studies use global "macro"-level measures (e.g., return to work), while others use "intermediate" measures (e.g., improved memory). These studies also have been limited by small sample size, failure to control for spontaneous recovery, and the unspecified effects of social contact. Nevertheless, a number of programs have been described and evaluated.

Cognitive exercises, including computer-assisted strategies, have been used to improve specific neuropsychological processes, predominantly attention, memory, and executive skills. Both randomized controlled studies and case reports have documented the success of these interventions using intermediate outcome measures. Certain studies using global outcome measures also support the use of computer-assisted exercises in cognitive rehabilitation.

Compensatory devices, such as memory books and electronic paging systems, are used both to improve particular cognitive functions and to compensate for specific deficits. Training to use these devices requires structured, sequenced, and repetitive practice. The efficacy of these interventions has been demonstrated.

Psychotherapy, an important component of a comprehensive rehabilitation program, is used to treat depression and loss of self-esteem associated with cognitive dysfunction. Psychotherapy should involve individuals with TBI, their family members, and significant others. Specific goals for this therapy emphasize emotional support, providing explanations of the injury and its effects, helping to achieve self-esteem in the context of realistic self-assessment, reducing denial, and increasing ability to relate to family and society. Although the use of psychotherapy has not been studied systematically in persons with TBI, support for its use comes from demonstrated efficacy for similar disorders in other populations.

Pharmacological agents may be useful in a variety of affective and behavioral disturbances associated with TBI. Although specific studies in persons with TBI are few, these agents are typically used in TBI for their direct and indirect pharmacological properties. People with TBI may be more likely to experience detrimental side effects from these drugs than people without TBI; therefore, additional caution should be used in prescribing and monitoring psychopharmacologic treatment.

Behavior modification has been used to address the personality and behavioral effects of TBI. It also has been used in retraining persons with TBI in social skills. Many descriptive studies and a single prospective clinical trial provide limited support for the efficacy of this approach.

The value of vocational rehabilitation strategies, such as short-term and long-term supported employment and job coaching, is indicated by observational studies. This is particularly important since return to work is among the most

significant outcomes of successful rehabilitation. Community colleges and other structured educational institutions may be valuable resources for some persons with TBI.

For children, most rehabilitation services occur in the school setting. Children with TBI frequently attend special education services. The effectiveness of these services for children with TBI has not been well studied. Unfortunately, problems specifically related to TBI in children frequently are not identified.

Comprehensive interdisciplinary rehabilitation treatment, provided by a diverse team of experienced professionals, is commonly used for persons with TBI. These programs use individually tailored interventions, both restorative and compensatory, in order to achieve both intermediate goals in cognitive functioning and larger scale (global) outcomes. This personalized approach leads to great difficulty in the scientific evaluation of effectiveness, because there is significant heterogeneity among both persons with TBI and their comprehensive treatment programs. Nonetheless, uncontrolled studies and one nonrandomized clinical trial support the effectiveness of these approaches.

Other interventions, such as structured adult education, nutritional support, music and art therapy, therapeutic recreation, acupuncture, and other alternative approaches, are used to treat persons with TBI. These methods are commonly used, but their efficacy has not been studied.

There are many reports of interventions for family members of individuals with TBI, including psychological and social support and education. Although no empiric studies have evaluated the efficacy of these interventions, they are supported by substantial clinical experience.

Despite the relative paucity of rigorous investigation and the heterogeneity of subjects, study design, and outcome, several common and consistently recurring themes emerge from a detailed review of the scientific evaluations of cognitive and behavioral rehabilitation interventions. Evidence supports

the use of certain cognitive and behavioral rehabilitation strategies for individuals with TBI in particular circumstances. These interventions share certain characteristics in that they are structured, systematic, goal-directed, and individualized and they involve learning, practice, social contact, and a relevant context. It is important to recognize that a great deal of the scientific evidence to support the use of these approaches derives from relatively limited studies that should be replicated in larger, more definitive clinical trials.

What Are Common Models of Comprehensive, Coordinated, Multidisciplinary Rehabilitation for People With TBI, What Is Their Scientific Basis, and What Is Known About Their Short- and Long-Term Outcomes?

There are numerous approaches to TBI rehabilitation; most involve a traditional medical perspective. Common acute phase approaches include ICU/acute trauma and neurosurgical care, acute inpatient hospital rehabilitation, and subacute in-hospital care, such as coma management. Postacute approaches to TBI rehabilitation include home-based rehabilitation, outpatient rehabilitation programs, community re-entry programs, comprehensive day treatment programs, residential community reintegration programs, and neurobehavioral programs. Beyond the traditional medical approach, TBI rehabilitation also includes supported living programs, independent living centers, clubhouse programs, rehabilitation within schools, and vocational rehabilitation.

An extensive literature has examined the effectiveness of comprehensive rehabilitation programs for persons with TBI. Unfortunately, most studies are not rigorous from a methodological standpoint, so conclusions regarding effectiveness must be approached with caution. Indeed, critical analysis of the literature on TBI rehabilitation yield only a few studies that suggest effectiveness under limited conditions. A major mitigating factor is that research in the area of TBI rehabilitation is exceedingly difficult to conduct, and it has been difficult to obtain funding. Adequate sample sizes and appropriate comparison groups are difficult to achieve in a clinical, rehabilitation environment. Therefore, the fact that most research to date has not been rigorous must not be interpreted to imply that rehabilitation programs are not effective.

A major limitation within the field of TBI rehabilitation is the narrow focus of current medical restoration approaches;

the focus tends to be on enhancing capabilities of persons with TBI to help them adapt to life circumstances. However, new models of rehabilitation emphasize the parallel importance of environmental modification in order to create enabling conditions for the individual. Unfortunately, enablement approaches are not yet common in the field of TBI rehabilitation, in part because of funding constraints. The current approaches to TBI rehabilitation are also limited by the fact that little attention has been paid to the needs of high-risk age groups (e.g., infants, adolescents, and the elderly) and their families. Similarly, there is little recognition that TBI is frequently a lifetime disability with varying rehabilitation needs over that lifetime. Improvements in the conceptual approaches to TBI rehabilitation are needed.

Another difficulty with current models of TBI rehabilitation pertains to the issue of access to rehabilitation services. Specifically, there is a wide discrepancy in the availability of TBI rehabilitation programs across geographic regions and a lack of knowledgeable professionals able to facilitate community-based rehabilitation. Frequently, there are problems accessing rehabilitation services in a timely manner, and major financial barriers make access to TBI rehabilitation services difficult for many individuals. These factors and others make it difficult for persons with TBI and their families to obtain the necessary community support and participate optimally in the rehabilitation process.

An additional shortcoming of current approaches to TBI rehabilitation involves limited opportunities for decision-making by persons with TBI and their families. Traditional medical rehabilitation environments often do not foster partnerships with persons with TBI or their significant others. Therefore, the current approaches frequently result in a sense of disenfranchisement due to a lack of shared participation in goal development and program design. In addition, information provided by clinicians to persons with TBI and their families is often insufficient. Fortunately, notable exceptions to this problem are beginning to emerge as rehabilitation environments start to adopt participatory action strategies for both research and treatment endeavors.

Based on the Answers to These Questions, What Can Be Recommended Regarding Rehabilitation Practices for People With TBI?

- Rehabilitation services should be matched to the needs, strengths, and capacities of each person with TBI and modified as those needs change over time.
- Rehabilitation programs for persons with moderate or severe TBI should be interdisciplinary and comprehensive.
- Rehabilitation of persons with TBI should include cognitive and behavioral assessment and intervention.
- Persons with TBI and their families should have the opportunity to play an integral role in the planning and design of their individualized rehabilitation programs and associated research endeavors.
- Persons with TBI should have access to rehabilitation services through the entire course of recovery, which may last for many years after the injury.
- Substance abuse evaluation and treatment should be a component of rehabilitation treatment programs.
- Medications used for behavioral management have significant side effects in persons with TBI, can impede rehabilitation progress, and therefore should be used only in compelling circumstances.
- Medications used for cognitive enhancement can be effective, but benefits should be carefully evaluated and documented in each individual.
- Community-based, nonmedical services should be components of the extended care and rehabilitation available to persons with TBI. These include but are not necessarily limited to clubhouses for socialization; day programs and social skill development programs; supported living programs and independent living centers; supported employment programs; formal education programs at all levels;

case manager programs to support practical life skill redevelopment and to help navigate through the public assistance and medical-rehabilitative care systems; and consumer, peer support programs.

- Families and significant others provide support for many people with TBI. To do so effectively, they themselves should receive support. This can include in-home assistance from home health aides or personal care attendants, daytime and overnight respite care, and ongoing counseling.
- Rehabilitation efforts should include modification of the individual's home, social, and work environments to enable fuller participation in all venues.
- Special programs are needed to identify and treat persons with mild TBI.
- Specialized, interdisciplinary, and comprehensive treatment programs are necessary to address the particular medical, rehabilitation, social, family, and educational needs of young and school-age children with TBI.
- Specialized, interdisciplinary, and comprehensive treatment programs are necessary to address the particular medical, rehabilitation, family, and social needs of persons older than age 65 with TBI.
- Educational programs are needed to increase the degree to which community care providers are aware of the problems experienced by persons with TBI.

What Research Is Needed to Guide the Rehabilitation of People With TBI?

- Epidemiological studies on the risk factors and incidence of TBI are needed for different age groups, gender, and race.
- The relationship between substance abuse and TBI should be studied.
- Existing CDC surveillance systems based on hospital discharge summaries or death records should be expanded to include emergency department encounters in order to augment the current database for research.
- Studies of the placement of persons with TBI in nursing homes and psychiatric facilities are needed to clarify what constitutes appropriate placement.
- The epidemiology of mild TBI should be studied.
- The duration, natural history, and life-course manifestations (neurological, cognitive, social, psychological, economic, etc.) of mild, moderate, and severe TBI should be studied.
- Gender differences in survival rates, patterns of severity, and long-term manifestations of TBI should be studied.
- The consequences and effects of rehabilitation after TBI in the elderly should be studied.
- The experience of minority group members with TBI should be studied.
- Research training is needed in the areas of injury epidemiology and clinical research in order to enhance the quality of all research related to TBI.
- The time course of TBI should be studied in animals with respect to injury severity, influence of age and gender, and effects of interventions.

- Research is needed on the appropriate timing of therapeutic interventions after TBI.
- Research is needed on the effectiveness of pharmacological interventions for the cognitive, behavioral, and emotional consequences of TBI.
- The neurobiology of TBI in humans should be studied with modern imaging techniques (e.g., positron emission tomography [PET] and functional magnetic resonance imaging [fMRI]) and correlated with neuropsychological findings.
- Promising treatments of TBI derived from animal studies should be tested in humans.
- The epidemiology and management of TBI in sports should be studied.
- Well-designed and controlled studies of the effectiveness of rehabilitation interventions are needed.
- Economic analysis of TBI, including major determinants of costs, is needed.
- Innovative rehabilitation interventions for TBI should be developed and studied.
- The predictors of quality of life for persons with TBI, their families, and significant others should be studied.
- Studies are needed to evaluate the relationship between specific cognitive deficits and global outcomes.
- Validation of generic health-related quality of life assessment instruments for use in TBI is needed, as well as the development and validation of TBI-specific instruments.
- Uniform standards and minimal data sets to describe injury type, severity, and significant interacting variables, which could provide a total injury profile across a continuum of recovery, should be developed.

- The relationship between the pathophysiology of TBI and the effectiveness of different interventions should be studied.
- The long-term consequences of TBI of varying severity, including the consequences of aging for a person with TBI, should be studied.
- The developmental impact of TBI in childhood with respect to the need for special education, mental health, and rehabilitation services should be studied.
- The effectiveness of community-based rehabilitation for persons with TBI should be studied.
- Severity risk-adjustment models for studies of persons with TBI should be established.
- The effectiveness of peer support for persons with TBI, their families, and significant others should be studied.
- Innovative study methodologies to assess the effectiveness of complex interventions for persons with TBI should be developed and evaluated.

Conclusions

- TBI is a heterogeneous disorder of major public health significance.
- Consequences of TBI can be lifelong.
- Given the large toll of TBI and absence of a cure, prevention is of paramount importance. Identification, intervention, and prevention of alcohol abuse and violence provide an important opportunity to reduce TBI and its effects.
- Rehabilitation services, matched to the needs of persons with TBI, and community- based nonmedical services are required to optimize outcomes over the course of recovery.
- Mild TBI is significantly underdiagnosed, and early intervention is often neglected.
- Persons with TBI, their families, and significant others are integral to the design and implementation of the rehabilitation process and research.
- Public and private funding for rehabilitation of persons with TBI should be adequate to meet acute and long-term needs.
- Access to needed long-term rehabilitation may be jeopardized by changes in payment methods for private insurance and public programs.
- Increased understanding of the mechanisms of TBI and recovery hold promise for new treatments.
- Well-designed and controlled studies are needed to evaluate benefits of different rehabilitation interventions.
- Basic and common classification systems of TBI are needed.
- The evaluation of TBI interventions will require innovative research methodologies.
- Funding for research on TBI needs to be increased.

Consensus Development Panel

Kristjan T. Ragnarsson, M.D.
Panel and Conference Chairperson
Lucy G. Moses Professor and Chairman
Department of Rehabilitation Medicine
Mount Sinai School of Medicine
New York, NY

William R. Clarke, Ph.D.
Professor of Biostatistics
Department of Preventive Medicine
University of Iowa
Iowa City, Iowa

Janet R. Daling, Ph.D.
Member and Professor
Department of Epidemiology
Fred Hutchinson Cancer Research Center
Seattle, Washington

Susan L. Garber, M.A., O.T.R.
Associate Professor
Department of Physical Medicine and Rehabilitation
Baylor College of Medicine
Houston, Texas

Candace F. Gustafson, R.N.
Institute for Cognative Prosthetics
Bala Cynwyd, Pennsylvania

Audrey L. Holland, Ph.D.
Professor
Department of Speech and Hearing Sciences
University of Arizona
Tucson, Arizona

Barry D. Jordan, M.D., M.P.H.
Associate Professor
Biobehavioral Research Center
Charles R. Drew University of Medicine
Los Angeles, California

Jerry C. Parker, Ph.D.*
Clinical Professor of Internal Medicine and Psychiatry and Neurology
University of Missouri–Columbia
School of Medicine
Columbia, Missouri

* Dr. Parker is an employee of the Department of Veterans Affairs at the Harry S. Truman Memorial Veterans' Hospital, Columbia, MO and is qualified to participate on a consensus panel through his academic affiliation.

Mark A. Riddle, M.D.
Associate Professor Psychiatry and Pediatrics
Director
Division of Child and Adolescent Psychiatry
Johns Hopkins University
School of Medicine
Baltimore, Maryland

Elliot J. Roth, M.D.
The Paul B. Magnuson Professor and Chairman
Department of Physical Medicine and Rehabilitation
Northwestern University Medical School
Senior Vice President and Medical Director
Rehabilitation Institute of Chicago
Chicago, Illinois

Speakers

Marsha Mailick Seltzer, Ph.D.
Professor
Waisman Center
University of Wisconsin–Madison
Madison, Wisconsin

Kit N. Simpson, Dr.P.H., M.P.H.
Professor
Medical University of South Carolina
Charleston, South Carolina

Steven L. Small, M.D., Ph.D.
Associate Professor
Department of Neurology
University of Maryland School of Medicine
Baltimore, Maryland

Barbara Therrien, Ph.D., R.N., F.A.A.N.
Associate Professor and Director
Center for Enhancement and Restoration of Cognitive Function
University of Michigan
School of Nursing
Ann Arbor, Michigan

Bruce E. Wexler, M.D.
Associate Professor
Department of Psychiatry
Connecticut Mental Health Center
Yale University School of Medicine
New Haven, Connecticut

Barbara P. Yawn, M.D., M.Sc.
Director of Research
Olmsted Medical Center
Rochester, Minnesota

John Banja, Ph.D.
Associate Professor
Coordinator of Clinical Ethics Education
Mary Switzer Distinguished Fellow
Center for Rehabilitation Medicine
Emory University School of Medicine
Atlanta, Georgia

Diana D. Cardenas, M.D.
Professor
Department of Rehabilitation Medicine
University of Washington
Seattle, Washington

Randall M. Chesnut, M.D.
Associate Professor and Director
Neurotrauma and Neurosurgical Critical Care
Department of Neurological Surgery
Oregon Health Sciences University
Portland, Oregon

D. Nathan Cope, M.D.
Senior Vice President
Chief Medical Officer
Paradigm Health Corporation
Concord, California

John D. Corrigan, Ph.D.
Professor
Department of Physical Medicine and Rehabilitation
Ohio State University
College of Medicine
Columbus, Ohio

Gerben DeJong, Ph.D.
Director
National Rehabilitation Hospital Research Center
Washington, District of Columbia

William T. Greenough, Ph.D.
Professor of Psychology, Psychiatry, and Cell and Structural Biology
Center for Advanced Study
University of Illinois
Beckman Institute
Urbana, Illinois

Allen W. Heinemann, Ph.D., ABPP
Professor
Department of Physical Medicine and Rehabilitation
Northwestern University School of Medicine
Associate Director of Research
Rehabilitation Institute of Chicago
Chicago, Illinois

Mark V. Johnston, Ph.D.
Director of Outcomes Research
Kessler Rehabilitation Research and Education Corporation
West Orange, New Jersey

Jess F. Kraus, Ph.D.
Professor
Director
Southern California Injury Prevention Research Center
UCLA School of Public Health
Los Angeles, California

Jeffrey S. Kreutzer, Ph.D., ABPP
Professor and Director
Rehabilitation Psychology and Neuropsychology
Medical College of Virginia
Virginia Commonwealth University
Richmond, Virginia

Harvey S. Levin, Ph.D.
Professor and Director of Research
Department of Physical Medicine and Rehabilitation
Baylor College of Medicine
Houston, Texas

Tracy K. McIntosh, Ph.D.
Professor
Department of Neurosurgery
University of Pennsylvania Medical Center
Philadelphia, Pennsylvania

Kenneth Ottenbacher, Ph.D.
Vice Dean
Office of the Dean
School of Allied Health Sciences
University of Texas at Galveston
Galveston, Texas

John T. Povlishock, Ph.D.
Professor and Chair
Department of Anatomy
Medical College of Virginia
Virginia Commonwealth University
Richmond, Virginia

George P. Prigatano, Ph.D.
Chair
Clinical Neuropsychology Department
Section of Neuropsychology
Barrow Neurological Institute
St. Joseph's Hospital and Medical Center
Phoenix, Arizona

Theresa M. Rankin
National Community Education
Brain Injury Association, Inc.
McLean, Virginia

Mitchell Rosenthal, Ph.D.
Administrator
Research and Education Administration
Rehabilitation Institute of Michigan
Wayne State University
Detroit, Michigan

Planning Committee

Ronald M. Ruff, Ph.D.
Director of Neurobehavioral Rehabilitation
St. Mary's Hospital and Medical Center
Associate Adjunct Professor
Department of Neurosurgery
University of California, San Francisco
San Francisco Clinical Neurosciences
San Francisco, California

Donald T. Stuss, Ph.D.
Vice President of Research
Baycrest Center
Director
Rotman Research Institute
Professor of Psychology and Medicine (Neurology)
University of Toronto
North York, Ontario
CANADA

David J. Thurman, M.D., M.P.H.
Medical Epidemiologist
Division of Acute Care, Rehabilitation Research, }and Disability Prevention
National Center for Injury Prevention and Control
Centers for Disease Control and Prevention
Atlanta, Georgia

John Whyte, M.D., Ph.D.
Director
Moss Rehabilitation Research Institute
Moss Rehabilitation Hospital
Philadelphia, Pennsylvania

Mark Ylvisaker, Ph.D.
Associate Professor
Department of Communication Disorders
College of St. Rose
Albany, New York

Duane Alexander, M.D.
Director
National Institute of Child Health and Human Development
National Institutes of Health
Bethesda, Maryland

Beth Ansel, Ph.D.
Health Scientist Administrator
National Institute on Deafness and Other Communication Disorders
National Institutes of Health
Bethesda, Maryland

Geoffrey Cheung, Ph.D.
Deputy Director
Office of Alternative Medicine
National Institutes of Health
Bethesda, Maryland

Mary Ellen Cheung, Ph.D.
Formerly: Division of Stroke, Trauma, and Neuro-degenerative Disorders
National Institute of Neurological Disorders and Stroke
Currently: Program Director
Biological Sciences and Career Development
National Institute of Child Health and Human Development
National Institutes of Health
Rockville, Maryland

Margaret Coopey, R.N., M.G.A., M.P.S.
Health Policy Analyst
Center for Practice and Technology Assessment
Agency for Health Care Policy and Research
Rockville, Maryland

Jerry M. Elliott
Program Management and Analysis Officer
Office of Medical Applications of Research
National Institutes of Health
Bethesda, Maryland

John H. Ferguson, M.D.
Director
Office of Medical Applications of Research
National Institutes of Health
Bethesda, Maryland

Marcus J. Fuhrer, Ph.D.
Director
National Center for Medical Rehabilitation Research
National Institute of Child Health and Human Development
National Institutes of Health
Rockville, Maryland

William H. Hall
Director of Communications
Office of Medical Applications of Research
National Institutes of Health
Bethesda, Maryland

Cassandra E. Henderson, M.D.
Guest Scientist
Division of Epidemiology, Statistics, and Prevention Research
National Institute of Child Health and Human Development
National Institutes of Health
Bethesda, Maryland

David Heppel, M.D.
Maternal and Child Health Bureau
Health Resources and Services Administration
Rockville, Maryland

Danuta Krotoski, Ph.D.
Chief of Basic Rehabilitation Medical Research Branch
National Center for Medical Rehabilitation Research
National Institute of Child Health and Human Development
National Institutes of Health
Rockville, Maryland

Toby S. Lawrence, R.P.T.
Program Manager
Medical Science Programs
National Institute on Disability and Rehabilitation Research
U.S. Department of Education
Washington, District of Columbia

L. Don Lehmkuhl, Ph.D.
The Institute for Rehabilitation and Research
Houston, Texas

Harvey S. Levin, Ph.D.
Professor and Director of Research
Department of Physical Medicine and Rehabilitation
Baylor College of Medicine
Houston, Texas

Kristjan T. Ragnarsson, M.D.
Lucy G. Moses Professor and Chairman
Department of Rehabilitation Medicine
Mount Sinai School of Medicine
New York, New York

Andrés Salazar, M.D.
Director
Defense and Veterans Head Injury Program
Walter Reed Army Medical Center
Washington, District of Columbia

Charles R. Sherman, Ph.D.
Deputy Director
Office of Medical Applications of Research
National Institutes of Health
Bethesda, Maryland

Hilary D. Sigmon, Ph.D., R.N.
Physiologist
Program Director
National Institute of Nursing Research
National Institutes of Health
Bethesda, Maryland

David J. Thurman, M.D., M.P.H
Medical Epidemiologist
Division of Acute Care, Rehabilitation Research, and Disability Prevention
National Center for Injury Prevention and Control
Centers for Disease Control and Prevention
Atlanta, Georgia

Stephen M. Tuel, M.D.
Director
Clinical Practices Program
National Center for Medical Rehabilitation Research
National Institute of Child Health and Human Development
National Institutes of Health
Rockville, Maryland

Benedetto Vitiello, M.D.
Chief
Child and Adolescent Treatment and Preventive Intervention Research Branch
Division of Services and Intervention Research
National Institute of Mental Health
Rockville, Maryland

Judith M. Whalen, M.P.A.
Associate Director for Science Policy, Analysis, and Communication
National Institute of Child Health and Human Development
National Institutes of Health
Bethesda, Maryland

John Whyte, M.D., Ph.D.
Director
Moss Rehabilitation Research Institute
Moss Rehabilitation Hospital
Philadelphia, Pennsylvania

George A. Zitnay, Ph.D.
President and Chief Executive Officer
The Brain Injury Association
Washington, District of Columbia

Lead Organizations

National Institute of Child Health and Human Development
Duane Alexander, M.D.
Director

Office of Medical Applications of Research
John H. Ferguson, M.D.
Director

Supporting Organizations

National Institute on Deafness and Other Communication Disorders
James F. Battey Jr., M.D., Ph.D.
Director

National Institute of Mental Health
Steven E. Hyman, M.D.
Director

National Institute of Neurological Disorders and Stroke
Gerald D. Fischbach, M.D.
Director

National Institute of Nursing Research
Patricia A. Grady, Ph.D., R.N.
Director

Office of Alternative Medicine
Wayne B. Jonas, M.D.
Director

Office of Research on Women's Health
Vivian W. Pinn, M.D.
Director

Agency for Health Care Policy and Research
John M. Eisenberg, M.D.
Administrator

Centers for Disease Control and Prevention
Jeffrey P. Koplan, M.D., M.P.H.
Director

Bibliography

The speakers listed above identified the following key references in developing their presentations for the consensus conference. A more complete bibliography prepared by the National Library of Medicine (NLM) at the NIH, along with the references below, was provided to the consensus panel for their consideration. The full NLM Bibliography is available at the following Web site: http://www.nlm.nih.gov/pubs/cbm/tbi.html.

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U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Public Health Service
National Institutes of Health
Office of Medical Applications of Research
Building 31, Room 1B03
31 Center Drive, MSC 2082
Bethesda, MD 20892-2082

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Rehabilitation of Persons with Traumatic Brain Injury

A Continuing Medical Education Activity Sponsored by the National Institutes of Health/Foundation for Advanced Education in the Sciences

OBJECTIVE

The objective of this NIH Consensus Statement is to inform the biomedical research and clinical practice communities of the results of the NIH Consensus Development Conference on Rehabilitation of Person with Traumatic Brain Injury. The statement provides state-of-the-art information regarding the appropriate use of rehabilitation procedures for persons with traumatic brain injury, and presents the conclusions and recommendations of the consensus panel regarding these issues. In addition, the statement identifies those areas of study that deserve further investigation. Upon completing this educational activity, the reader should possess a clear working clinical knowledge of the state-of-the-art regarding this topic.

ACCREDITATION

The National Institutes of Health/Foundation for Advanced Education in the Sciences is accredited by the Accreditation Council for Continuing Medical Education to sponsor continuing medical education for physicians.

The National Institutes of Health/Foundation for Advanced Education in the Sciences designates this educational activity for a maximum of one hour in Category 1 credit towards the AMA Physician's Recognition Award. Each physician should claim only those hours of credit that he/she actually spent in the educational activity.

EXPIRATION

This form must be completed and **postmarked by October 28, 2001**, for eligibility to receive continuing medical education credit for this continuing medical education activity. The expiration date for this test may be extended beyond October 28, 2001. Beginning October 29, 2001, please check the NIH Consensus Development Program web site (http://consensus.nih.gov) or call the NIH Office of Medical Applications of Research at 301-496-1144 for information regarding an extended expiration date for this continuing medical education activity.

INSTRUCTIONS

The consensus statement contains the correct answers to the following 14 questions. Select your answer(s) to each question and write the corresponding letter(s) in the answer space provided. Mail the completed test by the expiration date shown above to *CME Program, Office of Medical Applications of Research, National Institutes of Health, Building 31, Room 1B03, 31 Center Drive MSC 2082, Bethesda, MD 20892-2082*. You will receive notification of your test results within 2 to 3 weeks. If you have successfully completed the test (10 or more correct answers), you will receive a certificate for 1 hour of continuing education credit along with your test results. The estimated time to complete this educational activity is 1 hour. Photocopies of this form are acceptable. There is no fee for participating in this continuing education activity.

1. **Epidemiologic profiles of age, gender, ethnicity, severity, and cause indicate that TBI is very heterogeneous. Data indicate that:** *(You must indicate all that are true.)*
   a. Males are more than twice as likely as females to experience TBI.
   b. Alcohol has been reported to be associated with half of all TBI.
   c. Incidents involving motor vehicles, bicycles, or pedestrians cause 50 percent of TBI.
   d. Most cases of TBI related to sports or recreation do not require hospitalization.

   ANSWER(S): _____

2. **The cognitive consequences of TBI are variable in terms of their effects on individuals, may change in severity and presentation over time, but:**
   (You must indicate all that are true.)
   a. Memory impairment is not a persistent problem.
   b. Unrecognized problems in language use are common..
   c. Perceptual functioning or difficulties in attention are not affected.
   d. Frontal lobe functioning is not vulnerable to TBI.

   ANSWER(S): _____

3. **Common behavioral deficits reported after TBI include:**
   (You must indicate all that are true.)
   a. verbal and physical aggression
   b. limited self-awareness
   c. mood disorders and altered emotionality
   d. depression and anxiety

   ANSWER(S): _____

4. **As individuals who have suffered a TBI attempt to resume their usual daily activities, increasing demands are placed upon them. Spiraling adverse consequence of TBI may become apparent, not only in the affected individual, but also in family members. Depression, social isolation, and anger occur and affect family functioning and relationships.**
   a. True b. False

   ANSWER: _____

5. **For children with TBI, the interactions of physical, cognitive, and behavioral sequelae can interfere with acquisition of new learning, and the effects of early injury may not become apparent until later in the developmental process.**
   a. True b. False

   ANSWER: _____

6. **The biological consequences to the brain after TBI are multiple and complex and the course of recovery is related to these events:** *(You must indicate all that are true.)*
   a. Many chemical changes occur within axons and neurons after TBI; however, calcium is not affected.
   b. Beta amyloid, a protein present in neurons in Alzheimer's disease, can be deposited in neurons after TBI.
   c. Excitatory neurotransmitters (glutamate and aspartate) are reported to occur in large amounts in the brain after TBI.
   d. Alterations in neurotransmitter systems involving acetylcholine, serotonin, or dopamine would not be expected to affect cognition or behavior.

   ANSWER(S): _____

7. **Studies that delineate the basic mechanisms of injury and examine the cellular plasticity among neurons and their connections indicate that the injured brain has some capacity to recover.**

   a. True b. False

   ANSWER: _____

8. **Cognitive recovery from TBI proceeds in overlapping stages and challenges in designing a program of rehabilitation include:** *(You must indicate all that are true.)*

   a. The temporal course of recovery is lengthy, and may have substages that relate to particular pathophysiology.
   b. Cell death (apoptosis) and plastic changes in circuitry only occur very early after TBI.
   c. Specific interventions may have beneficial effects at certain times and not others.
   d. All rehabilitative interventions should be started in the early stages after TBI.

   ANSWER(S): _____

9. **Interventions shown to improve cognitive deficits after traumatic brain injury include:** *(You must indicate all that are true.)*

   a. Cognitive exercises targeted to memory and attention
   b. Computer-assisted cognitive remediation
   c. Compensatory devices such as memory books and electronic paging devices
   d. No interventions have been shown effective

   ANSWER(S): _____

10. **Psychotherapy after traumatic brain injury:** *(You must indicate all that are true.)*

    a. Is important to treat depression, anxiety and loss of self-esteem
    b. Treats cognitive deficits
    c. Should also involve family members
    d. Has not been tested in double-blind randomized trials

    ANSWER(S): _____

11. **Behavioral disorders that result from traumatic brain injury include:** *(You must indicate all that are true.)*

    a. Aggressiveness
    b. Apathy
    c. Personality change
    d. Disinhibition

    ANSWER(S): _____

12. **Comprehensive interdisciplinary rehabilitation of traumatic brain injury is generally individualized to the patient rather than using structured protocols.**

    a. True b. False

    ANSWER: _____

13. **Pharmacotherapy after traumatic brain injury is limited by proven detrimental side effects in traumatic brain injury patients.**

    a. True b. False

    ANSWER: _____

14. Important components of traumatic brain injury rehabilitation include:
(You must indicate all that are true.)

a. Interdisciplinary and comprehensive nature
b. Strictly protocol driven
c. Families are central in planning and design of programs
d. Substance abuse evaluation and treatment
e. Strong behavioral control through medications in most cases

ANSWER(S): _____

Your response to the following four questions is optional and will have no effect on the grading results of this test.

To what extent did this CME activity meet the stated objectives?

a. not at all
b. very little
c. somewhat
d. considerably
e. completely

ANSWER: _____

To what extent will participation in this CME activity enhance your professional effectiveness?

a. not at all
b. very little
c. somewhat
d. considerably
e. completely
f. does not apply

ANSWER: _____

Do you have additional comments you think would enhance the utility or impact of this NIH Consensus Statement?

_____

Are there new topics you would like to have covered in a similar or related NIH Consensus Development Conference or Statement?

_____

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