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Clinical Continuum of Care and Natural History

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SCOPE OF THE PROBLEM AND THE CHARACTERISTICS OF TRAUMATIC BRAIN INJURY

Systems of care for patients with traumatic brain injury (TBI) must account for the particular characteristics of this disorder. First, TBI is among the most common of serious, disabling neurological disorders. It is a significant problem in all societies. In the United States at least 1.4 million TBIs occur every year, and there are 5.3 million people living with disability from TBI (1–3). (See Thurman et al., Chapter 6, for a full discussion of the epidemiology of TBI). Systems of care must allocate resources for the large number of people who are affected by the disorder.

Second, TBI is largely a younger and older person's disorder (2). Individuals younger than 30, mostly males, make up the largest proportion of those affected. TBI usually impacts people who are in the later stages of adolescent development or in early adulthood. Therefore, TBI typically disrupts important periods of life involving educational and social development, emerging vocational productivity and adult independence, and beginning spousal relationships and family development. Older persons present particular problems related to aging including co-morbidities, slower and less complete recovery, and vulnerability to complications of injury and treatment (4) (see Englander et al., Chapter 21 on "The Older Adult").

Systems of care must address needs that include special educational requirements, independent living, vocational training and supports, and supports for family members.

Third, TBI commonly affects people with preexisting problems such as substance abuse, learning disabilities, behavioral disorders, psychiatric disorders and other risk factors that may make people more prone to injuries. In addition, persons with brain injury are more prone to psychiatric co-morbidities and psychosocial difficulties following injury. Systems of care must consider these pre-injury and post-injury issues with respect to injury prevention, their interactions with the clinical effects of injury and potential detrimental influence on recovery from TBI.

Fourth, the most important and consistent effects of TBI involve cognitive, emotional, and behavioral functioning. Motor and sensory perceptual problems also occur in varying amounts, more likely in those with more severe injuries. Cognitive and behavioral problems present more challenges to the health care system because they are often more difficult to recognize, characterize, and treat than traditional medical and physical problems. Persons with TBI, particularly less severe injuries, may not have any obvious physical markers of the injury, though there may be profound effects on the individual's ability to function, largely resulting from cognitive or behavioral dysfunction. Criteria for medical rehabilitation reimbursement, length of stay, and utilization decisions are

often more focused on motor issues affecting function and less focused on cognitive and behavioral treatment issues. Some insurance payers even exclude coverage for cognitive rehabilitation, although there is evidence to support its efficacy (5, 6) (see Cicerone, Chapter 41 on cognitive rehabilitation). Systems of care must focus on proper assessment and treatment of cognitive and behavioral problems, even though they may not fit the characteristics of medical rehabilitative systems that were originally developed for medical and physical disabilities (see Chapters 41–45).

Fifth, TBI, especially more severe injuries, can have a relatively extended natural history and lifelong effects. Recovery from TBI may be more protracted, over a relative longer portion of the lifespan, than most other acquired injuries or neurological disorders that evolve more quickly or typically affect persons at later stages of life. Thus, systems of care for TBI need to recognize the potentially prolonged recovery timetable. Further, recovery after TBI has a somewhat predictable and characteristic course, with a variety of recognizable cognitive, behavioral, and sensorimotor syndromes at different stages. An appreciation of the natural history of TBI is essential to assessing the individual and to effectively applying treatment and services at different stages of recovery, as well to avoiding treatment that may be unnecessary or ineffective (see discussion on natural history below).

Finally, TBI is a disorder with a wide variety of pathophysiological effects, a range of severities, and a multitude of problems that may occur as the result of injury. Persons with apparently similar injuries may have significant variation in their presentation, course of recovery, response to interventions and ability to return to functioning. Systems of care should have a breadth of treatments and services to address the variety of problems that can occur after TBI, and the flexibility to move persons through the system in different ways depending on their individual needs at different times post-injury.

THE DEVELOPMENT OF SYSTEMS OF CARE

The provision of a comprehensive continuum of care for persons with TBI is an enormous challenge given the characteristics of TBI outlined above and the wide range of services that should be provided to large numbers of people, over relatively longer periods than most other disorders. The challenge confronts many groups: persons with TBI and their families; clinicians managing the care of the patient with TBI; service providers attempting to provide efficient and effective care; health insurance providers; public and other payers balancing coverage needs with financial pressures; and society at large, making choices about resource allocation and costs. Resources for patients with TBI include: acute and post-acute medical

care; rehabilitative services in the hospital, at home, in the community, and in residential settings; psychosocial services; educational and vocational services; and a variety of other support services.

The development of systems of care for persons with TBI evolved in the 1970s and 1980s. In part, the systems that developed for care of patients with TBI were influenced by systems of care that were developed for those with spinal cord injury (SCI). Prior to development of specific programs for persons with TBI, patients were frequently treated in psychiatric facilities, nursing homes, or more general rehabilitation facilities. The Rehabilitation Services Administration and NIDHR (which was to become NIDRR), which had funded SCI model systems in the early 1970s, also funded two model system projects for TBI in 1978 at Stanford University and New York University (7). The recommendations from these projects helped to promote the development of interdisciplinary, dedicated TBI programs with services across the continuum of recovery. As programs began to develop, the lack of organized planning led to an initiative by the NIDRR under the Department of Education in 1987 to fund five TBI model systems demonstration projects (8). This has expanded to sixteen TBI Model Systems Projects throughout the country in part aimed at gathering information to improve comprehensive systems of care for patients with TBI. The components of these model systems of care includes emergency medical services, acute neurosurgical care, comprehensive rehabilitation services, long-term interdisciplinary follow-up and rehabilitation services, as well as what were termed optional services, including behavior modification programs, home rehabilitation services, case management and community living options (8). A key portion of this program has been longitudinal and project specific based research.

Beginning in the mid-1980s, the Commission on Accreditation of Rehabilitation Facilities (CARF) developed standards for TBI rehabilitative care by establishing specialized accreditation for TBI programs. It now accredits TBI programs in six categories: inpatient, outpatient, home- and community-based, residential, long-term residential, and vocational.

An important development in TBI care was the TBI Act of 1996 passed by Congress to “provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury.” Four provisions of the Act included surveillance and prevention under the CDC; basic and applied research to improve diagnosis, therapeutics and the continuum of clinical care conducted by the NIH; a planning and implementation grant program to the states under the Health Resources and Services Administration (HRSA); and a Consensus Conference conducted by the Center for Medical Rehabilitation and Research at NIH (9). The NIH consensus conference panel addressed the continuum of

care for TBI in their conclusions. The recommendations included that “persons with TBI should have access to rehabilitation services through the entire course of recovery, which may last for many years after the injury” and that “community-based, non-medical services should be components of the extended care and rehabilitation available to persons with TBI” (10).

REALITIES OF THE MARKETPLACE

Although demonstration projects such as the TBI Model Systems have presented apparently effective systems of care for persons with TBI, the realities of the marketplace in the United States have presented challenges to providing such care and services to all those in need. Corrigan outlined 20 important challenges to meeting the needs of persons with TBI, within the categories of access, availability, appropriateness, and acceptability (9). With regard to access, the problems involve identifying and utilizing services, even if they are available. There may be difficulties accessing information about available resources. Sometimes it is difficult to determine what resources are covered by health insurance, and sometimes coverage is denied even after services are delivered. Families and care providers usually lack roadmaps to guide access to appropriate resources, and points of entry into publicly funded systems may be unclear. Service systems may have artificial barriers created by narrow eligibility criteria. Services are often fragmented and not well coordinated.

Corrigan pointed out a number of availability issues for which the main limiting factor is funding. Health insurance may not cover needed services that are available, or may direct individuals to centers that are less familiar with the care of persons with TBI. Further, lack of payer support may preclude the availability of some services to begin with. Many persons with TBI have no health care funding at all at the time of injury, and present state budget constraints are further threatening the Medicaid program. When available, health insurance typically fully covers acute care, but coverage for rehabilitative care becomes incrementally more difficult across the continuum of care, from inpatient to outpatient to residential and community services. Health insurance coverage also tends to be more restrictive for cognitive and behavioral services as opposed to more traditional physical rehabilitative and medical treatment. In many cases, coverage for services has to shift from private to public sources such as Medicaid and Medicare over the course of recovery because of limits in coverage for longer term care in many policies. Public funding has further restraints on long-term coverage. Several states have developed a system of Medicaid waivers to provide long-term home and community-based services that would otherwise be covered only for institutional settings, such as nursing

homes. The fragmentation and limitations in financing of care and services can create a nightmare of coordination for persons with brain injury, their families, and service providers. Clinicians who coordinate care for persons with brain injury must become aware of the complexities of reimbursement and the array of alternative sources of funding for TBI care and support in their community.

Other issues affecting the availability of services include geographic limitations; lack of transportation; a paucity of appropriate, affordable housing; limitations in resources for behavioral problems in children with special needs; and the long-term needs of persons with TBI (9). Patients with TBI in rural communities have special challenges in finding services within a reasonable distance. Even when available in a nearby area, transport to and from these services can be a major problem, and home services may not be available or sufficiently expert for this population. The ability to provide a full array of services to all age groups within a reasonable proximity, with full funding support, is an enormous challenge that may never be fully satisfied.

The appropriateness of available resources is also a common problem. Sometimes the reason for inappropriate services is dictated by payer constraints. For instance, because the main payer for long-term care services is Medicaid, if waivers to support home and community services are not available, patients with TBI who cannot return home may be placed in nursing homes, even though community-based services may be more appropriate. Even if services are available, programs and professional providers may lack the knowledge and expertise to serve this population. Generalists in a particular discipline or specialty may not have the skills for proper assessment or treatment of the patient with TBI. Accreditation programs such as CARF and the American Academy of Certified Brain Injury Specialists (AACBIS) have attempted to set standards and credentialing to assure appropriateness of programming and expertise. (See also Chapter 4 on training and certification.) Nevertheless, such expertise may simply not be available in some geographic areas or at certain levels of care. Sometimes erroneous services are applied because of this lack of expertise, but at times services may be improperly or needlessly applied even by those with expertise. Inaccurate diagnosis, inappropriate application of treatment at a particular stage of recovery, use of unproven or ineffective treatments, or application of effective treatment to those for whom it would not be of benefit are examples. Use of accurate diagnosis and prognosis is necessary to avoid some of these problems of inappropriate treatment (see below on natural history). Sometimes services are not fully relevant to a person’s and family’s needs at a particular time or in a particular environment. The acceptability of these services to the goals of the person with TBI and how services promote the persons self-actualization is another challenge to the TBI service marketplace (9).

ESSENTIAL COMPONENTS OF THE CLINICAL CONTINUUM

The continuum of care for patients with TBI occurs in a variety of settings. Figure 1-1 illustrates the different types of care and how patients may move through these components. The flow through these services may not be linear. Patients may enter or leave the system of care at different points, or reverse directions, based on individual needs or the dictates of the marketplace.

Prevention

The earliest aspect of the care continuum involves public health issues prior to injury occurrence. Injury prevention is an essential part of trauma care systems. The TBI Act of 1996 charged the CDC with the responsibility for prevention, in addition to surveillance, to assess factors that increase the risk of TBI and those that are protective. Injury prevention programs generally include three components: programs designed to alter behavior and improve decision-making to increase self-protection; product improvement to minimize the chance of injury or protect the individual

in an accident; and legislation and public policies that require individuals to follow safety guidelines. Prevention of TBI includes a number of efforts such as reducing alcohol-related injuries, preventing falls, preventing violence, promoting safe practices in sports, promoting helmet and seatbelt use, enhancing safe driving practices, and improving vehicle safety. (See Napolitano et al., Chapter 7, for a discussion of primary prevention.)

Emergency Medical Services

Since the 1980s, emergency trauma systems have developed throughout the United States and have led to improved survival and recovery (11–13). Mortality for those that reach the hospital has been reduced from nearly 50% to about 25% (13). Regional trauma systems have developed to promote quick evacuation using ground or air transport to level I and level II trauma centers from the field, or from level III and IV trauma centers when necessary for more serious injuries. The level I and II trauma centers have full-time intensive care, imaging, neurosurgical, and other trauma subspecialists. The Brain Trauma Foundation’s (BTF) Guidelines for Prehospital

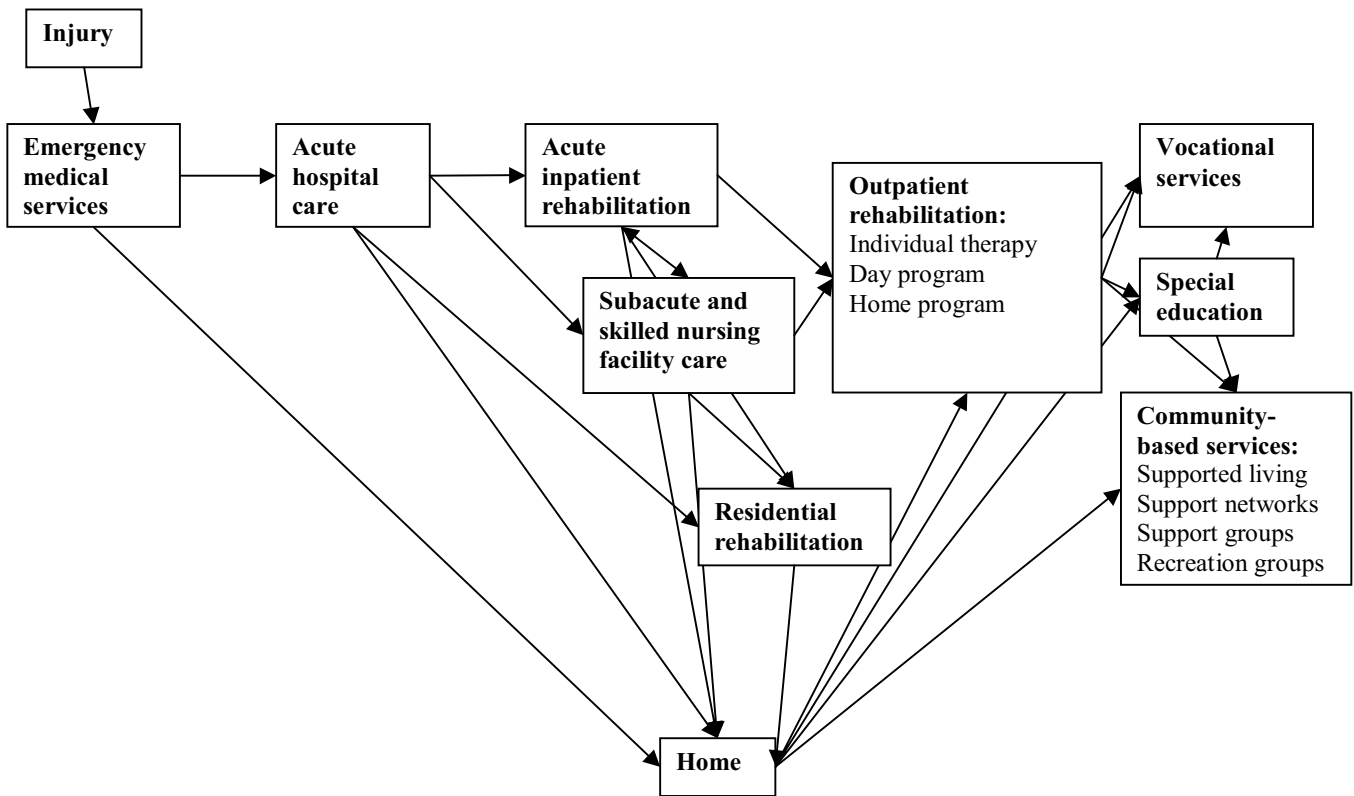


FIGURE 1-1

Usual flow of patients through the clinical continuum of care. Choices of services and direction of flow will be based on severity, stage of recovery, patient’s needs, availability of resources, availability of home and community supports, and constraints of the marketplace

Management of Traumatic Brain Injury have played a role in improving emergency prehospital care (12). Although improved, proper diagnosis, patient education, and referral for appropriate follow-up is still lacking for many patients (14).

Acute Hospital Care

Patients with TBI who are admitted for acute hospital care range from those who need a period of observation to recognize secondary neurological deterioration and neurosurgical complications that may ensue after a delay, to those with co-morbidities that require hospital care, to those with more severe brain injury that requires intensive care management. Acute neurosurgical and intensive care for patients with TBI have improved over the last two decades with better survival and outcomes (15). Evidence-based guidelines for acute TBI care, including the use of intracranial pressure monitoring, have contributed to better outcomes (16–18). (See also Chapters 18 and 19 on acute care.)

Rehabilitation assessment and early rehabilitative interventions should take place a short time after admission, in the acute hospital setting. Subsequent decisions for rehabilitative care are made as the patient progresses toward medical and surgical stability, when the severity of the injury and the clinical rehabilitation needs become more apparent. The pathway toward acute inpatient rehabilitation versus outpatient or subacute care is largely based on injury severity and pace of recovery. Generally, patients with severe injuries (e.g., unconsciousness for a day or more, or post-traumatic amnesia and confusional states of at least days to weeks, or patients with large focal lesions) move to acute inpatient rehabilitation facilities. Constraints related to marketplace issues may affect this decision. For instance, some health care plans will not support admission to inpatient rehabilitation facilities if a patient has few traditional physical rehabilitation needs (e.g., needs little or no help ambulating) even if the patient has profound cognitive and behavioral disturbances related to the injury. Patients with mild injuries generally return home and may need outpatient rehabilitation services. A proportion of patients with moderate injury may benefit from at least a brief inpatient rehabilitation stay, depending on their circumstances. Patients who are slower to recover may require extended care in the acute hospital, or be transferred to subacute or skilled nursing facility (SNF) care instead of inpatient rehabilitation. In many systems such persons may be lost to the follow-up of those with a primary interest in caring for patients with TBI. Strong consideration should be given to transferring such patients to facilities with special expertise in the assessment and care of patients who are unconscious or minimally conscious (usually in acute inpatient rehabilitation or specialized subacute facilities), because these

patients are vulnerable to secondary complications and may have significant potential for further recovery, albeit at a slower pace.

Acute Inpatient Rehabilitation

Acute inpatient rehabilitation may occur on general rehabilitation units or in dedicated brain injury units that are within acute care facilities or part of freestanding rehabilitation hospitals (inpatient rehabilitation facilities or long-term care hospitals). Admission criteria to hospital-based acute inpatient rehabilitation involve the following:

1. an intensity of medical and nursing care needs that requires full-time physician monitoring and specialized rehabilitative nursing expertise;
2. functional deficits that would benefit from a higher level of rehabilitation treatment intensity (usually designated at a minimum duration of 3 hours a day).

Patients are best served in programs dedicated to brain injury care or those with a significant proportion of staff with expertise in managing brain injury. Rehabilitation teams usually include: case managers; physical, occupational, and speech therapy staff; rehabilitation nurses; nursing assistants; psychologists; neuropsychologists; rehabilitation physicians (usually a physiatrist, rehabilitation neurologist, or neuropsychiatrist); primary care physicians; and a variety of other consultant medical specialists. Other disciplines such as social workers, rehabilitation technicians, therapy assistants, behavior specialists, recreation therapists, other subspecialty therapists, chaplains, and attorneys may also contribute to care.

Expertise in managing behavioral problems and assuring patient, family and staff safety is important because patients in agitated confusional states are usually managed at this level of care (see below). Family education to familiarize them with the problems and needs of persons with brain injury is essential at this level of care, especially for those that will transition home from acute inpatient rehabilitation. The decision regarding the next level of care depends on the patient's medical stability, level of dependency, safety, and whether the person's needs can be adequately met at home or requires further institutional care. Patients with severe TBI typically still require some supervision and, perhaps, physical assistance for self-care and mobility when they are ready to be discharged from acute inpatient rehabilitation.

Subacute and Skilled Nursing Facility Rehabilitation

Patients with TBI are usually admitted to this level of care from acute hospital care or acute inpatient rehabilitation. Therapies are provided at a lower level of intensity than in

acute inpatient rehabilitation and the level of medical monitoring is less frequent than acute inpatient rehabilitation. There are many programs at this level that specialize in neurorehabilitation and it is certainly preferable if this level of care occurs in programs with special expertise in brain injury management. Specialized neurobehavioral treatment units in SNFs are available in some areas for patients with more persistent behavioral regulation problems.

As noted above, some SNFs may offer specialized care for patients with TBI with prolonged impairments of consciousness. The availability of specialized subacute and SNF facilities may be limited in some areas because of market constraints. Care for the needs of TBI patients in these settings may be costly, exceeding the usual reimbursement standards for this level of care. Alternative funding sources or variance in reimbursement standards may be necessary to maintain more specialized subacute or SNF care.

Often, SNF level rehabilitation care takes place in more general facilities, and frequently younger patients with TBI are in the minority among an older group of patients with other disorders, such as dementia. Lengths of stay at this level of care varies but usually lasts one or more months; a minority of patients transition to unskilled residential levels of care at the same facilities. A large proportion of patients transition home and may go on to outpatient rehabilitation or other outpatient services.

Outpatient Rehabilitation

Outpatient rehabilitation can take on a number of different forms. Sometimes it consists of individual therapies involving physical, occupational and speech therapists. There may be other available services including psychology, neuropsychology and therapeutic recreation. The team may be led by a case manager, and they may provide other coordinated activities such as group treatments. Usually rehabilitation at this level is less coordinated than inpatient treatment and therapists provide care more autonomously. This type of care may occur in the setting of the home through visiting nurse or other agencies, or on the premises of an acute hospital, a rehabilitation hospital, or an outpatient rehabilitation facility.

A more coordinated form of outpatient rehabilitation may take place in a day program, with a full array of therapies, group treatments and group activities, case management, and regular team meetings to set goals and review progress. More holistic programs may include a psychotherapeutic milieu associated with the therapy programming. These programs are often in naturalistic, community settings and take advantage of this location to set up activities to foster community reentry treatment goals.

The length and intensity of treatment is determined by the patient's needs but is largely constrained by health insurance payer contracts and public funding policies limiting duration of care and range of covered services.

Following outpatient rehabilitation, additional community-based services may be provided.

Residential Rehabilitation

Group residence programs may provide services at various stages after injury. These programs may offer individual therapies and group therapies, as well as resources to foster independent living skills. Residential programs may be aimed at patients recently discharged from acute hospital settings or acute inpatient rehabilitation, or those later in the process of recovery who cannot be in their own home setting, and who require a structured, supervised setting and specialized programming cannot be in their own home setting. There are usually only part-time nursing services and programs may or may not provide physician services. Those states with more generous auto insurance benefits tend to have more extensive residential programs. Staffing includes a mix of professional therapists, other professional disciplines, and lay staff. Patients may progress in levels of independence in these setting and go back home or to other long-term living arrangements, such as supported living (see "Other Community-Based Services" below), after this level of care.

Vocational Services

For most persons with TBI, the return to work is the most important long-term rehabilitation goal and measure of treatment success. Returning to some sort of productive activity is an essential part of societal reintegration and life satisfaction after brain injury and an important part of the continuum of care. In the United States, the states receive federal money to operate vocational rehabilitation programs to provide vocational rehabilitation services to individuals with disabilities. Services support reeducation, training and worksite support services. Even those with severe injuries, who may not qualify for regular marketplace jobs, are eligible for services under this mandate. Supported employment has become one of the important vocational rehabilitation strategies for getting persons with disabilities back to employment in regular work sites. These services are most successful when coordinated with outpatient rehabilitative care and assessments. Many of these programs have been underfunded and it has been a problem to provide the intensive ongoing supports that are necessary to keep some persons with TBI employed. Many states have adopted innovative programs to extend funding using resources such as Medicaid waivers to improve services and employment retention (19).

Special Education

Education services are a necessary component of the continuum of care for children and adolescents with TBI.

TBI became a part of the federal Individuals with Disability Education Act in 1990. This federal law mandates that the education needs of school age children with TBI, among other disabilities, will be provided in the public schools and must include any necessary rehabilitation services. Services should be planned and monitored using an individualized educational program (IEP). Students often transition from inpatient or outpatient rehabilitation to school-based services, sometimes beginning with home tutoring. Ylvisaker and colleagues have made a number of recommendations for assessment, intervention, student support, educator training, family support and system flexibility to better serve the particular educational and rehabilitative needs of students after TBI (20).

Other Community-Based Services

Persons with TBI may require other ongoing care and support after formal rehabilitative care has ended. These home and community-based services are more fragmented and less readily available. Patients who are unable to live independently, and who are not relying on home supervision by family or friends, require supported living environments. Previously, because Medicaid has been the primary funder of long-term care, this meant placement in nursing homes, usually a poor alternative for younger persons with TBI. A growing number of states with Medicaid waiver programs have been able to provide supported living services in the community using such models as supervised group homes, foster homes, and personal care attendants. A number of other models have been developed.

Community support networks and support groups for persons with TBI and their families are important resources. One such support network, the Clubhouse Model, adapted for persons with TBI in the 1980s from the psychiatric community, provides a setting for members and volunteers to participate in social, recreational, and work-related activities. It has been a cost-effective method to promote practical, functional living skills. Support groups for persons with TBI and their families are often sponsored by state chapters of the Brain Injury Association of America (BIAA).

Other necessary community services include provisions for transportation for those who are unable to drive or ride public transportation. Respite care to provide time-off for full-time caretakers of persons with severe disability after TBI is another important need. Legal services, financial and estate planning, mental health services, and treatment of substance abuse must also be considered part of community-based system of care for people with TBI.

Case Management

Fragmentation and lack of coordination of care is one of the major problems in finding and applying proper

services for the individual with TBI. Case managers within institutions and in the community play an essential role in coordinating services. Case managers collaborate with others, including patients, families, providers, and payers to assess, plan, implement, coordinate and monitor services to meet an individual's needs and promote favorable outcomes in a cost-effective manner. In addition to coordinating care within the TBI system, case managers must coordinate treatment in other areas such as chronic pain, mental health and other medical specialty areas. Case managers and life care planners may develop proposals outlining the anticipated lifelong care needs of persons with TBI (see Weed and Berens, Chapter 66, on life care planning).

SERVICE DELIVERY IN RELATION TO NATURAL HISTORY OF TBI

Accurate diagnosis and an appreciation of the natural history of TBI are useful in formulating treatment plans and assuring appropriateness of services along the continuum of care. This effort involves assessing a person's brain injury in the context of pathophysiologic damage, associated clinical neurobehavioral syndromes, stage of recovery and anticipated course of recovery, based on knowledge of brain-behavior relationships and natural history (21). The formulation must also consider interaction with non-injury factors such as age and psychosocial issues, associated injuries, premorbid problems, co-morbidities, and later complications.

This understanding helps in determining where the patient is along the path of recovery and in projecting expectations for subsequent recovery to inform treatment planning with respect to treatment setting, treatment strategies, treatment goals, and length of stay. It may also help avoid unnecessary treatment of problems that may be expected to resolve as part of the natural course of recovery (e.g., post-traumatic amnesia or confusional agitation) or impairments with a poor prognosis that may not recover with direct treatment (e.g., amnesia after extensive, bilateral hippocampal injury or behavior dysregulation after massive bilateral orbital prefrontal and temporal polar damage).

Such an understanding of natural history also helps determine when clinical syndromes do not fit the expected path of recovery, suggesting possible secondary neurological complications (e.g. hydrocephalus, chronic subdural hematomas), the influence of noninjury factors (medical, iatrogenic or psychogenic), or misdiagnosis of injury type and severity. The clinical natural history of TBI can be defined in the context of focal or diffuse neuropathologic events. (See Kochenak et al., Chapter 8, for an extended discussion of TBI neuropathology.) The critical pathophysiologic factors are the type, distribution,

severity, and location of these combined neuropathological events after brain injury.

Although focal and diffuse pathological processes are often intermingled and have common secondary and metabolic consequences, it is useful to consider them separately for the purposes of clinical diagnosis. The precision of diagnosis varies and may be challenging, especially with respect to diffuse and secondary injuries, for which there are as yet no readily available, direct clinical, diagnostic probes.

Diffuse Injury

Diffuse axonal injury represents the main diffuse pathological process, but it is associated with a host of associated pathophysiological phenomena (see Chapter 8). The natural history of diffuse injury is characterized by a recognizable pattern of stages that occur across the wide spectrum of severity. Injury severity determines the duration of recovery stages and levels of impairment at each stage of recovery. These stages can be combined into three principal phases of recovery from the acute to chronic stages:

1. loss of consciousness (LOC);
2. post-traumatic confusion and amnesia (PTA);
3. post-confusional restoration of cognitive function.

These form the basis for the main indices of clinical severity for TBI. These indices can help project a rough approximations for the time course of recovery and the probabilities for a particular outcome (22–26). The three phases of recovery appear to be proportionally related in patients with diffuse injury; each subsequent phase is typically several-fold longer than the previous one (22). Their proportionality in patients with diffuse injury, although variable, can contribute to predicting the time course of recovery. For instance, there was a predictable relationship between the duration of unconsciousness (LOC) and duration of confusion/PTA in a series of patients with diffuse injury defined by a linear regression model that predicted nearly 60% of the variance — $PTA (wks) = 0.4 \times LOC (days) + 3.6$ (22). This model was confirmed in a separate cohort of 228 patients (27). Longer PTA was observed in older patients, especially over age 40, or if a focal frontal lesion was present. Predicting PTA may aid rehabilitative treatment planning with respect to length of stay decisions, treatment choices for confusional agitation, and other treatment issues at this stage of recovery.

Patients with the least severe diffuse injuries (mild concussion) evolve through LOC (if complete loss of consciousness occurs at all) in seconds to minutes and through PTA usually in minutes to hours, followed by a post-confusional phase typically lasting days to weeks. In

mild TBI the transition through the earliest stages may be brief, unwitnessed, and difficult to document. Patients with severe TBI may require days to weeks to evolve through LOC, weeks to months to resolve confusion and PTA, and months to years to evolve through the post-confusional residual recovery phase. The course of recovery after severe TBI is among the longest observed after neurological damage. Dynamic changes in neuropsychological functioning have been observed as long as 5 years post-injury (28–31). Some patients with very severe injuries may stall in recovery at some stage in this process (e.g., permanent vegetative state (32) or minimally conscious state (33)).

This pattern of recovery has been delineated in stages according to various schemas. The most widely used is the Rancho Los Amigos levels of cognitive functioning (34). (See Table 1-1.) Another schema, first proposed by Alexander (35) and further modified (referred to as the Braintree scale) (21, 36), follows more traditional neurological nomenclature. (See Table 1-2.) As patients progress through these stages the principal defining cognitive limitations evolve from deficits in arousal and consciousness, to basic attention and anterograde amnesia, to higher-level attention, memory, executive functioning, processing speed, insight, and social awareness (37).

The first stage of recovery is *coma*, a state of unconsciousness without spontaneous eye opening. This corresponds to Rancho level I. Patients with diffuse axonal injury are unconscious at the outset, without lucid interval. The depth of coma in the time period shortly after injury, as measured by the Glasgow Coma Scale (GCS), is one of the common markers of injury severity and prognosis.

Almost all persons with severe TBI who survive resume spontaneous eye opening and sleep/wake cycles while still unconscious, a condition termed a *vegetative state* or Rancho level II. Except for the small percentage of very severely injured patients who remain permanently vegetative, evidence of awareness and purposeful behavior resume, often heralded by visual fixation and tracking. The ability to follow commands is the usual convincing

TABLE 1-1
Rancho Los Amigo Levels of Cognitive Functioning After TBI (34)

I.	No response
II.	Generalized responses
III.	Localized responses
IV.	Confused – agitated
V.	Confused – inappropriate
VI.	Confused – appropriate
VII.	Automatic – appropriate
VIII.	Purposeful and appropriate

TABLE 1-2
Braintree Neurologic Stages of Recovery from Diffuse TBI (and corresponding Rancho Los Amigos Scale Levels) [settings of care]

1. *Coma*: unresponsive, eyes closed, no sign of wakefulness (Rancho 1) [emergency medical services; acute inpatient hospital]
2. *Vegetative state/wakeful unconsciousness*: no cognitive awareness; gross wakefulness, sleep-wake cycles begin (Rancho 2) [acute hospital; acute inpatient rehabilitation; subacute rehabilitation]
3. *Minimally conscious state*: inconsistent, simple purposeful behavior, inconsistent response to commands begin; often mute (Rancho 3) [acute hospital; acute inpatient rehabilitation; subacute rehabilitation]
4. *Confusional state*: interactive communication and appropriate object use begin; amnesic (PTA), severe basic attentional deficits, hypokinetic or agitated, labile behavior; later, more appropriate goal-directed behavior with continuing anterograde amnesia (Rancho 4, 5, partly 6) [acute hospital; acute inpatient rehabilitation]
5. *Post-confusional/emerging independence*: marked by resolution of PTA; cognitive impairments in higher-level attention, memory retrieval and executive functioning; deficits in self-awareness, social awareness, behavioral and emotional regulation; achieving functional independence in daily self care, improving social interaction; developing independence at home (Rancho 6 & partly 7) [acute inpatient rehabilitation; subacute inpatient rehabilitation; outpatient rehabilitation; residential treatment; outpatient day hospital and community reentry]
6. *Social competence/community reentry*: marked by resumption of basic household independence; developing independence in community, household management skills and later returning to academic or vocational pursuits; recovering higher level cognitive abilities (divided attention, cognitive speed, executive functioning), self-awareness, social skills; developing effective adaptation and compensation for residual problems (Rancho 7& 8) [outpatient community reentry programs; community-based services – vocational; special education; supported living services; mental health services]

marker of restored consciousness. Almost all patients with some loss of consciousness will be evaluated and treated by emergency medical services. Those with brief alterations of consciousness (e.g., seconds or minutes) may be discharged home. Patients with more prolonged LOC or more complicated injuries (e.g., focal lesions, other injuries) will likely be admitted for acute inpatient care, often beginning in surgical intensive care units, usually supervised by neurosurgical or surgical trauma specialists.

For patients recovering slowly, cognitive responsiveness may begin erratically and inconsistently, without any reliable interactive communication. This stage may be called a *minimally conscious state* and corresponds to Rancho level III (33). Many patients at this stage will continue in acute medical care settings and some who are slower to recover will transition to rehabilitation facilities, including acute inpatient rehabilitation, subacute rehabilitation, long-term care hospitals or skilled nursing facilities. (See also Chapter 25 on disorders of consciousness.)

When purposeful cognition is unequivocally established, basic attention and new learning remain severely impaired. This clinical condition may be labeled a *confusional state* and corresponds to Rancho levels IV, V, and part of VI. At this stage, patients are often highly distractible, with poorly regulated behavior. They may rapidly escalate to agitated behavior (Rancho IV). Less often, patients may remain in a state of underactivated, hypokinetic, withdrawn behavior. Dense anterograde

amnesia also defines this stage; patients are disoriented, have little or no moment-to-moment episodic recall and display little or no ability to learn new information after even a brief delay (posttraumatic amnesia). As this stage evolves, patients are better able to focus attention and regulate behavior (Rancho V). The end of this stage is characterized by a significant improvement in focused and sustained attention, reliable orientation, and resumption of continuous, day-to-day memory, albeit still somewhat defective (Rancho VI). Patients at this period of recovery are appropriate for care in dedicated TBI units in acute inpatient rehabilitation. Towards the end of this period of recovery, transition to home and outpatient rehabilitation programs should be contemplated. Patients who are transitioning slowly, or who still require significant amounts of supervision and assistance that may not be feasible at home, may require continued institutional treatment, perhaps at a skilled nursing facility or a residential treatment facility. Some may transition to an outpatient day program.

The *post-confusional* stages of recovery are characterized by a gradual improvement in cognitive and behavioral functioning in those with more severe injuries. This phase of recovery may be further broken into stages of *emerging independence*, as patients' cognitive abilities, self-awareness, and insight allow independence in self-care and safe unsupervised activity at home (Rancho level VII), and a stage of *social competence and community reentry*, with restoration of the capacity for independent function in the community or at the higher-level demands

of school or the workplace (Rancho level VIII). Services at these stages of care include outpatient therapies, day programs, community-reentry programs, residential treatment, and a variety of community-based services.

Focal Injury

Focal cortical contusions, deep cerebral hemorrhages, and extraaxial (subdural and epidural) hemorrhages make up the majority of focal lesions after TBI. The time course of natural history of focal injury resembles that of vascular lesions of other causes, particularly hemorrhagic stroke, but the clinical consequences of focal injury after TBI are characteristic, owing to the predilection of lesions in the anterior and inferior portions of the frontal and temporal lobes. The acute phase involves edema and other early secondary pathophysiological phenomena which are maximal over the first few days post-injury. The resulting effects may include confusion and, perhaps, decreased arousal, especially if a mass effect compromises diencephalic and mesencephalic structures. Otherwise primary focal pathology is not directly associated with loss of consciousness.

As edema and other secondary effects wane over the first three weeks, more specific localizing effects of focal damage become more apparent. Recovery during this subacute phase is maximal over the first 3 months, but improvement may continue at a slower rate over many months. The size and depth of focal lesions, their laterality and the potential for reorganization within the neural networks affected by the damage, all in large part determine the time course and outcome.

Damage to limbic neocortical and heteromodal areas of the frontal and temporal lobes determines the usual effects of focal TBI on cognitive and behavioral functioning. The residual syndromes of prefrontal lesions include alterations in affect and behavior (e.g., disinhibition or apathy) impairment in attention, working memory and memory retrieval, and dysfunctional higher-level cognition (e.g., executive functions, insight, social awareness). Lesions in anterior and inferior temporal areas may also contribute to affective and behavioral disturbances. Larger lesions extending to medial temporal areas may produce specific impairments in memory encoding and retrieval (amnesia). Other localizing temporal syndromes involve extension of lesions into auditory association areas (e.g., aphasia, with left hemisphere lesions) and visual association areas (e.g., visual agnosias, especially with bilateral lesions).

The clinical syndromes associated with focal lesions are often embedded in the evolving effects of diffuse injury, if both types of injury are combined. Particularly with more severe and diffuse injuries, the overall outcome is driven largely by the effects of diffuse rather than focal injury (38). In patients with mild to moderate diffuse injury, large focal lesions may have more influence on recovery (39–41). Characterization of the localizing

syndromes associated with focal lesions may be difficult until unmasked after resolution of post-traumatic confusion. Another difficulty in isolating the effects of focal lesions is that neurobehavioral syndromes may be identical to those related to diffuse injury (e.g., dysexecutive syndrome, behavioral dysregulation) because these same areas, especially their axonal projections, are affected by diffuse pathology (42).

Although the problems may be similar, recovery and prognosis may be different. For instance, features of the frontal lobe syndrome, may be more persistent in patients with frontal contusion (43, 44). Levin et al. (45) observed that although other aspects of recovery were similar, unilateral frontal lesions adversely affect psychosocial outcome in children with TBI compared to those without focal frontal lesions. These aspects of diagnosis and prognosis related to focal lesions should also help inform rehabilitation planning. For example, behavioral regulation problems related to bilateral frontal and temporal focal lesions may be more persistent and thus demand more active early intervention and treatment planning over a longer horizon than similar problems that might occur after diffuse injury, which may be expected to resolve more successfully as the stages of recovery evolve.

SUMMARY AND CONCLUSIONS

The provision of a continuum of care for persons with TBI is an enormous challenge given the numbers of people affected by the disorder (patients, family members, and others), the potential long-term course of recovery, the possible life-long effects (often beginning at an earlier stage of life), and the wide variety of types of brain damage, clinical effects, and associated problems. Systems of care for TBI involve coordination of numerous services utilizing many disciplines across the range of severities and course of recovery. These services include prevention; emergency, acute, early, and later rehabilitation; vocational, educational, and community support; and long-term care. A number of marketplace factors constrain the full development and availability of components of these systems for persons in need, most notably cost, payer support, and availability of resources. These constraints become progressively restrictive for services and supports beyond the acute treatment period.

An understanding of brain injury, its clinical consequences, associated problems and complications, and natural history of recovery helps in applying proper services for patients along the continuum of care, and helps assure more effective use of resources. Ongoing efforts at fruitful research to determine which interventions are most effective, for whom, and at what periods of time, will be essential to refine the best clinical practices possible along the continuum of care.

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