

BRAIN INJURY REHABILITATION; THE CONTINUUM OF CARE

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Introduction

The dramatic increase in the survival rate from traumatic brain injury began in the mid-nineteen seventies. Chances for survival can be directly attributed to improved emergency medical services and diagnostic capability. Unfortunately, the ability to effectively treat the deficits which remained from the injury did not develop simultaneously with the ability to save and sustain those lives.

This was a new population, which was unlike any other. However, this difference would not be recognized until several years later. Out of expediency, ignorance and lack of alternatives, the individuals with traumatic brain injury were being treated, for the most part, in acute hospitals and rehabilitation facilities using protocols for stroke patients. Many of these individuals were eventually sent to traditional skilled nursing homes and mixed in with the geriatric residents. Others were deemed unmanageable and were referred to locked psychiatric units.

In the late 1970s, insightful individuals recognized the shortcomings of the then existing treatment systems. They developed protocols, utilizing different sites to more effectively deliver services to this population. This was the beginning of the next step in the "continuum" of care for brain injured individuals.

It should be understood that this "continuum" of care is not linear. One does not progress through all phases of the recovery process and neatly transition from one level to the next. This is the challenge-determining who fits where and at what time.

Some specialty treatment programs developed in traditional acute hospitals and rehabilitation facilities. Other alternative programs

ABSTRACT

The continuum of care for individuals with traumatic brain injury has become quite complex. Medical technology has increased survival rates leaving many individuals with severe deficits. Quality treatment programs have been developed that are proving cost effective with good outcomes for many. To insure maximal recovery from traumatic brain injury, the patient should be provided the opportunity for treatment in the setting which is most conducive to maximal recovery. The acute hospital, the subacute program, the postacute program, the home program and the others should all be considered as part of the continuum of care for the brain injured individual.

Timely movement to the appropriate setting will facilitate maximum recovery of a traumatic brain injured individual. Many patients have the potential to improve with quality treatment, appropriate setting and sufficient time to be treated. The article describes the levels of care that are available, with the goals and objectives of each level. It describes the patient that would best fit into each level. It further identifies assessment tools that are useful in measuring progress and outcomes.

are developed in skilled nursing and residential group homes, and in rural, isolated ranches. The most recent programs are carried out in the survivors' own homes.

The authors will describe the different levels of care and attempt to provide guidelines as to who might be an appropriate candidate for a particular level of care. Timely movement within the continuum is key to cost containment. Providers and payers alike must be aware of the available levels of care and the admission criteria for each respective level if timely movement is to take place.

Acute hospital

Emergency room: According to the National Head Injury Foundation, there are hundreds of thousands of individuals who require medical attention annually for traumatic brain injury. The severity of these injuries can range from what appears to be a simple "knock on the head" accompanied by a momentary loss of consciousness to severe injury with resultant persistent vegetative state.

The moderate and severe injuries will be followed very closely in the acute setting and the impact on the individuals and their loved ones will not be disputed. Problems which result from the "mild traumatic brain injury" may be a very differ-

ent matter. Some individuals develop significant residual deficits. They may be unable to return to previous employment, or undergo personality changes, suffer memory loss, depression, etc., all from a simple "knock on the head."

It is the responsibility of the traumatic brain injury providers to help educate the emergency departments, as well as the primary care providers of the signs, symptoms, and treatment of "mild traumatic brain injury." Few emergency rooms have the knowl-

edge or the resources available within the community that will help direct these patients into appropriate treatment.

Intensive care unit: For the moderate to severe traumatic brain injured individual, the intensive care unit (ICU) is the most likely next step in the continuum of care. In the ICU, the life and death issues will be addressed along with the guilt, anger, and frustration of the family. The ICU can be the beginning of the process of identification of treatment providers, sites, and financial resources to aid in the patient's recovery.

Early involvement of a physiatrist to determine the most effective treatment approaches is recommended. Physical therapy has long been recognized as an effective intervention to reduce the complications of muscle contractures. Occupational therapy can provide splinting to decrease the contractures that develop in the wrists and fingers. Speech therapy can begin oral motor functions to enhance swallow, as well as developing a communication system.

Following medical stabilization, but while still in the ICU, social services, case management, and brain injury support group members should be brought in to assist the family. Time and again, families have remarked they have been preparing for their loved one to die but do not know how to prepare when he or she continues to live. The family wants the best answers but can usually accept the "I don't know." Bringing in professionals and knowledgeable lay people can help comfort the family and prepare them for the possible answers to the unaskable questions.

The ICU is the level of care where analysis of the prognostic indicators can begin in earnest. "The best guide to the severity of this damage is the degree and duration of altered consciousness¹." Other indicators include the Glasgow coma scale score, presence of skull fracture, and other trauma.

For the low level or slow to recover patients, speech pathologists and other trained professionals can use sophisticated assessment tools. The Glasgow coma scale is familiar to most professionals in the emergency room and the ICU. A somewhat less familiar evaluation is, the western neuro care sensory stimulation profile (WNSSP)², monitors discrete change in function. While the Glasgow coma score is useful in the first 72 hours, subtle changes are not as apparent as with the WNSSP.

Coma stimulation can also be introduced in the ICU. Though it has not been proven to be definitively effective, it has also not proven harmful and individuals might benefit. Medication that stimulates the reticular activating system might be helpful, though no comprehensive controlled trials have been published. A recent federal court decision held that an insurer cannot deny a claim for coma stimulation because it is "experimental."³

Rehabilitative services in the intensive care unit can provide essential functions to minimize complications and help facilitate awakening and begin to heal both the patient and the family.

Medical stability is the key indicator of readiness for transfer. The degree of stability will dictate the destination to acute hospital, acute rehabilitation, or subacute care if available.

Acute medical unit: At this level of care, medical stabilization will continue. It is imperative that complications be prevented and/or minimized. A feeding gastrostomy may be preferable to nasal gastric feeding tubes. All potential sources of infections, e.g., foley catheters, should be minimized, if possible. Medications that alter the level of cognition and consciousness should be used sparingly. Nutritional levels should be closely monitored.

Rehabilitation nursing as well as all appropriate therapeutic disciplines should remain involved, as in ICU, possibly at a higher level of intensity.

Acute rehabilitation unit or hospital: Once the patient is medically stable and making appropriate gains, he or she might be considered for this level of care. Payers and families must be aware that this level of care has very strict admission criteria, as defined by Medicare,⁴ some of which are:

- Requires a multidisciplinary, coordinated team approach to upgrade his/her ability to function;
- Ability to tolerate and benefit from at least three hours of interdisciplinary therapy per day;
- Requires close medical supervision by a physician with specialized training or experience in rehabilitation;
- Requires 24-hour rehabilitation nursing;
- Demonstrates good potential to show significant practical improvement; and
- Demonstrates good potential to meet realistic goals.

It should always be kept in mind that this level of care is preparatory to a next step in the continuum: home, and community, outpatient, day treatment, transitional, behavioral or subacute. The next level will be contingent not only on the recovery status but on the financial resources available.

In selecting an acute rehabilitation hospital or unit, the reader is referred to the article, "Centers of Excellence: How to Choose the Appropriate Rehabilitation Facility."⁵

Subacute care

What is subacute care? There are numerous providers furnishing what they call subacute care. The current working definition by the American Subacute Care Association (ASCA):⁶

"Subacute care patients are sufficiently stabilized to no longer require acute care services but are too complex for treatment in a traditional nursing center. Subacute care centers and programs typically treat patients who present with rehabilitative needs or are medically complex and require physiological monitoring.

Subacute care patients may require:

- Treatment and/or assessment of the care plan by a physician;
- Nursing intervention more than three hours per day; and/or
- Therapy services (i.e. physical therapy, occupational therapy, speech therapy, respiratory therapy, or psycho-social); and
- The need for ancillary or technological services (i.e. laboratory, pharmacy, nutrition, diagnostic, DME); and
- Utilization of case management and coordination of services.

Individuals at the subacute level of care are most effectively and appropriately served by an outcome-oriented interdisciplinary treatment team and treatment process. Subacute care programs are focused on outcomes of functional restoration, clinical stabilization and avoidance of acute hospitalization and medical complications.

A subacute level of care can be provided in a variety of settings, including skilled nursing facilities, acute hospitals and specialty hospitals. The objectives and goals of subacute care are the cost effective and creative use of health care resources to achieve maximal outcomes."

The above definition could encompass all treatment that was necessary when a patient was medically stable but too complex for a traditional nursing home. In theory, all rehabilitative services could be included in this definition. Many acute hospitals have designated subacute units, while many freestanding skilled nursing facilities are now calling themselves subacute. Some states recognize this level of care for reimbursement under their respective Medicaid (MediCal) programs. The authors will attempt to define each level as it applies to the brain injured patient. Acute rehabilitation hospitals have been addressed above.

The most appropriate brain injured patients for this level of care are usually the low level and slow to progress. Patients with a Rancho los Amigos Cognitive Level I through IV are usually the most appropriate. Occasionally, those individuals progressing slowly through levels V and VI can be found here.

Patients may enter directly from the intensive care unit still on ventilators. They usually require comprehensive management in nutrition and prevention of pulmonary, skin, bowel and bladder problems. Some patients may first go to an acute rehabilitation hospital then to the subacute unit or vice versa. Many subacute patients will require long term or even life long management at this level. However, some do progress to a level where acute hospital rehabilitation is again needed or even surpasses that level with placement in a transitional center being warranted.

The appropriate patient for this level is one who requires more care than the traditional nursing home normally provides, re-

quires specialized care and would benefit from a limited amount (less than three hours per day) of multidisciplinary/interdisciplinary therapeutic intervention. The therapists can either be employees of the program or on contract. In some instances, the frequency and intensity of therapy can match or even exceed that which is provided in an acute rehabilitation hospital, depending on the particular program.

Generally, registered nursing hours are less than acute rehabilitation hospitals and units. For example, Medicare requires acute rehabilitation hospitals to provide a minimum of 5.5 actual nurse contact hours whereas, in a freestanding subacute unit to qualify for subacute reimbursement under MediCal (state Medicaid), at least 3.8 actual nurse contact hours are required in addition to a minimum daily average of 2.0 certified nurse assistant hours. There is also a requirement that there be at least one registered nurse per shift. The traditional skilled nursing home requires only 2.2 nursing contact hours.

The majority of these units are not specifically for brain injured individuals. Some programs may have distinct services and personnel trained in brain injury, while others do not. The providers, case managers and payers must be aware of the capabilities of the subacute programs in their respective areas in order to make appropriate referrals.

Skilled nursing facility/ subacute: The authors have selected to make this a separate category. The real difference between nursing home—subacute and the traditional nursing home is staffing patterns and the ability to competently handle complex medical problems.

Previously, medically complex patients, those on ventilators, requiring total parental nutrition, having tracheostomies, gastrostomies, etc., were maintained in acute medical settings. This is no longer the case. The traumatically brain injured individual who is not an appropriate candidate for acute rehabilitation may meet admission criteria for the subacute level of care.

Hospital/ subacute unit/ distinct part: This is usually a designated unit of a larger hospital that will take longer to recover brain injured individuals. There may or may not be an acute rehabilitation unit affiliated with the hospital. The unit may have its beds licensed as acute hospital or skilled nursing beds, depending upon jurisdiction.

In California, under MediCal subacute requirements, a minimum daily average of 4.0 nursing contact hours is required. There is also a requirement of at least a 2.0 daily average of certified nurse assistant hours with at least one registered nurse per shift.

The vast majority of the hospital based programs have salaried therapists that treat patients daily. The cost of these programs will depend on the amount of direct therapy given by professional therapists.

Residential homes (subacute): Group homes have been used for many years for the higher level brain injured patient. In California legislation was approved for a group home setting for the low level patient. This unique level of care provides services that equate to subacute programs in hospitals and skilled nursing facilities.

In relatively large single family dwellings (approximately 5000 square feet) programming is provided in a home like environment. There are usually six to 10 patients per group home. The direct nursing care and certified assistant hours are slightly higher in this setting due to the small number of patients.

This program was designed specifically for brain injured and neurologically impaired individuals. The original concept was to provide a comfortable atmosphere to meet the long term care needs of clients who were complex and did not fit chronologically or diagnostically into the traditional nursing home.

Therapy services are usually contracted by the facility. The experience of the therapist can be a variable. Therapist hours also vary with the abilities of the patient and can be as frequent as daily.

Personal homes: Most families have a desire to take their loved one home after traumatic brain injury, regardless of level of recovery. Some patients have returned home at a very low level of function. Families contemplating this decision should be made aware of the care requirements for their loved one and the consequences of an action that will disrupt almost all facets of normalcy and family dynamics.

If a low level functioning patient is cared for in a private home setting, the home will literally be transformed into the primary care center. This might, and probably will, entail all the paraphernalia of a hospital room, including, hospital bed, ventilator, IV stands, wheelchair, medications, etc. In addition, privacy will be sacrificed as care givers will be required for a major portion of every day.

Companies have been established to meet the needs of individuals in their personal homes. These companies have staff trained to meet most levels of care. This is more than the traditional home health agency. Nursing staff and therapists will come to the home and provide the care. This can be an option for some families though the authors do not recommend it for low functioning patients, primarily due to the cost of care and disruption to the family. When the injured individual is cared for in the home, there is no time or place for respite for the family. This level of care is most appropriate for those who can maintain some independence but need further treatment and training in the home environment.

Post acute/ transitional facilities

During the late 1970s the first post acute brain injury programs opened. The realization that rehabilitation hospitals and tradi-

tional outpatient treatment were not working to mainstream brain injured individuals back to society had mandated a new approach.

Patients appropriate for this level of care are generally higher functioning and require supervision. They usually have minimal physical impairment but judgment and thinking processes may be so impaired as to render them unsafe to be left unsupervised. They may not be conscious of their own safety. They usually have short-term memory deficits and some will have non-productive behavior.

The goal for patients at this level of the continuum will be to become independent in basic living skills. Some will attain full independence and employment, while others may need to continue to live in a supportive environment. All should become independent in mobility and basic activities of daily living.

These post acute programs were developed specifically for the treatment of brain injured individuals. They can be found in numerous settings. Because programs are not all the same, selection should be done carefully, matching the needs of the brain injured individual with the program.

While all of these programs are designated for treatment of brain injured individuals, their emphasis will differ. Some programs may have a strong behavior component while others might stress ability to cope with physical disability, or have a strong vocational focus. As with all programs, the referral source needs to know the needs of their patients and the capabilities of the respective treatment programs.

The abilities, premorbid and post injury, of the patient should determine the placement of the patient. Generally, upon completion of one of these programs, the individual should be able to live semi-independently. He or she might require limited support in understanding financial matters, e.g., budgeting. The patient should have had an introduction or training in prevocational and/or vocational activities. Some will return to the job market, possibly in supportive employment or a volunteer situation. Some may need additional education in a school setting. Brain injured individuals who reach a high level of functioning can benefit from some type of transitional program.

Group home: Group homes are usually large, single family residences that provide housing for up to six residents. They are staffed by what are called life skill trainers (LSTs) The LSTs are generally non-licensed or non-credentialed personnel who supervise the activities of the residents. Supervision of the LSTs is generally provided by licensed, experienced therapists.

The brain injured individual will have group and individual therapy either in the group home or at an independent site, away from the facility. The therapies and activities are usually provided all day and into the early evening hours. The patients will learn or relearn how to socialize, use public transportation, manage money, perform household chores and generally "get on with living."

Apartments: The apartment concept is similar to that of the group home. The treatment program will buy or lease a block of apartments for the exclusive use of program patients. One apartment will serve as the base for the life skill trainers. The patient will either have his or her own apartment or will share it with another patient. The therapy facilities are usually at a different location and depending on their level of safety awareness, the patients will be provided transportation or taught how to use public transportation to commute.

Therapy may also be provided at the apartment. Independent living skills, e.g., cooking and housekeeping are appropriately taught in the apartments. Evening activities, as in the group home, enhance community reentry. Those who support the apartment "model" claim that this model might be better than the group home model as it provides more environmental validity. The patient must get up, get dressed and get out to daily activities—as they would in their normal, real world life.

Ranch: One of the oldest post acute transitional programs began on a ranch. The concept was to give the brain injured individuals an isolated secure environment with appropriate therapies including the involvement of animals indigenous to the ranch. The residential component and therapies are usually provided at the ranch. Caring for animals has proven to be very therapeutic for some individuals.

Generally, there does not seem to be a significant difference between the ranch, apartment, and group home models. The authors do not endorse any one model, but rather stress the importance of matching the needs of the patient to the appropriate therapeutic environment or model.

Behavioral program: All brain injured, as well as able bodied, individuals have some behavioral problems. Behavior is viewed as a "problem" depending upon whether it is productive or counter productive. For those brain injured individuals who have counter productive behavior, there are specialized programs. Treatment goals are similar to those mentioned previously, though all treatment and free time activities are developed with behavioral modification as part of the goals.

If the brain injured individual's behavior is such that it cannot be controlled with a behavioral approach, the use of psychotropic medications might need to be considered. As a last resort, placement in a locked psychiatric facility might prove to be necessary. It is important that the psychiatric facility have an understanding of the needs of the traumatic brain injured individual.

Day treatment: Day treatment usually involves transitional treatment at an outpatient facility. The treatment normally lasts all day, five days per week with community reentry skill building as the emphasis. Criteria for admission to this level of the continuum is usually the ability to live in a home environment with minimal difficulty. Some brain injured individuals may transit from a residential facility to a day treatment program. The individuals with

mild traumatic brain injury are very well suited for day treatment programs.

Community and home: Community and home is not synonymous with home health therapy, traditionally associated with Medicare patients. Treatment is usually done in the community or at the brain injured individual's private residence, similar in format to day treatment. These programs are useful when group dynamics and milieu are not required.

This level of care in the continuum is most appropriate for the slow to recover, who is at home and requires fine tuning of his or her home and community skills or for the high level patient who has significant memory impairment and can benefit from constant repetition of a task in a familiar environment.

Traditional outpatient: Treatment sessions are usually scheduled three times per week and then tapered in frequency as progress is made. Criteria for this level of care includes a limited amount of memory impairment and the ability to follow through with a home treatment program. The majority of brain injured individuals have such significant memory deficits that this level of care may not be appropriate initially. As memory improves, this level of care can be very beneficial.

Employment

The treatment team in all settings should assess the brain injured individual's potential to perform in the work place. Once the appropriate work setting is identified, a volunteer position in a similar job site should be considered. This will provide the patient and therapists with valuable information to enhance strengths, minimize weaknesses and provide the brain injured individual with relevant feedback regarding their deficits.

Supported employment has gained wide recognition. In a supported employment situation, the brain injured individual uses a "job coach" to work with them at the work site. Supported employment eliminates the need for close monitoring by the supervisor while allowing the job coach to assess the quality and quantity of the job performance. Job coaching enhances rebuilding skills for task completion and improves employer satisfaction.

Sheltered workshops: Sheltered workshops have been associated with the developmentally disabled for decades. There are sheltered workshops that have been set up to meet the specific needs of the brain injured. These programs are most successful with some clients having "graduated" to competitive employment.

As with all brain injury treatment programs, sheltered workshops need to be specific to the brain injured population. Many patients have commented that 'they are not retarded and do not belong in this environment.' Several sheltered workshops have been established specifically for the brain injured individual. Some

of these are free standing and some are associated with transitional centers.

After care or long-term care

Brain injured individuals should not be left to their own resources following discharge from institutional care. Support can be provided by trained individuals who assist the patient with monitoring of ongoing issues of daily living. Case managers, personal managers or family members can monitor progress. A qualified physician should be available to assist with the long term care issues as they might arise.

Having the skills to be employable does not preclude needing support in their home environment. The needed support can range from minimal assistance to enhancing their personal psychosocial image to providing meal preparation and household maintenance. Some brain injured individuals will become employable but need to live in a supportive environment.

One of the major areas is psycho-social adjustment. Many patients have difficulty trying to deal with their new personality and deficit. Group and individual counseling is sometimes needed to minimize these conflicts.

Some individuals will require some sort of supported living. They may be competitively employed but have problems with money management and transportation. They may need assistance with proper nutrition, etc. Supported living can be anywhere from a group home to individual apartments. Trained life skills attendants assist with the problem areas, under supervision of a qualified case manager and physician.

For the low level or vegetative patient, they can very well remain in a subacute setting. This will depend on the family and finances.

Summary

The continuum of care for the brain injured individual is quite complex. As stated earlier, progress is not linear. An individual may make steady progress and receive treatment in most of the programs mentioned. It is just as possible for an individual to skip entire levels in the continuum or to stop progressing altogether. It must be understood that there are no time frames in brain injury rehabilitation. Treatment may last a lifetime.

As the patient improves, he or she should be transferred to the next least restrictive and cost effective program. Transition through the continuum should be guided by the needs of the patient, and quality treatment provided by staff trained in brain injury rehabilitation in an appropriate environment. Quality medical management through good case management can facilitate the care the brain injured client requires.

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