

DEBUNKING TEN MYTHS OF "RECOVERY"

~from CH2 "The Nature of Head Injury" by Thomas Kay, Ph.D. and Muriel Lezak, Ph.D., the book is entitled "Traumatic Brain Injury and Vocational Rehabilitation", Published by The Research and Training Center, University of Wisconsin-Stout.

Myth #1: The Concept of "Recovery"

Throughout this chapter we avoid such phrases as "recovery after head injury," There is a reason for this. Most people's experience, and therefore expectations, regarding illness and injury is one of temporary reduction in functioning, followed by a gradual return to normalcy. People get sick, go to hospital, and get better. Bones are broken, casts applied for a period, muscle strength regained over several months, and scars fade.

When commonplace notion of recovery is applied to head injury, however, considerable harm can be done. Almost never does a patient "recover;" the residual deficits are usually significant and permanent. The continual expectation of recovery can lead clients and families into denial, frustration, disappointment, and even worse, extremely unrealistic expectations and planning.

Moreover, the successful rehabilitation of the head injured person cannot take place until they and their family are aware of the new limitations, accept them, and formulate new goals based on changed expectations.

To speak of, and implicitly believe in and hold out the hope for recovery as defined in the first paragraph can severely impede this process. Of course, this process of awareness and acceptance, on the part of the family, is a process that takes time. Certainly families, especially in the early stages, must hold out hope. However, we prefer to speak in terms of hope for as much improvement as possible, to build in realistic expectations from the beginning.

Myth #2: Recovery Occurs in a Year

It was a traditional rule of thumb for physicians to tell patients and families that "whatever recovery will occur will happen in the first 12 months." This was probably based on the observation that the neurological examination at one year was quite predictive of neurological status years later. Neuropsychological research unwittingly advanced this myth by looking at groups of head injured patients and discovering that the group mean on certain tests stabilized at about one year. Unfortunately, families understood all this to mean that functional recovery stopped after a year.

Nothing could be further from the truth. First, more careful research seems to show that the duration of improvement varies as a function of severity of injury; less severe injuries improve more quickly, more severe injuries more slowly.

Second, group averages hide individual variations. While the average group score on a test may not change significantly after a year, individuals within that group may continue to improve.

Third, neither neurological nor cognitive status is the same as functional ability. Often, it is the environmental changes that occur years later --the death of a parent, the establishment of a relationship, the establishment of a new local program-- that is the trigger for a spurt in functional gain.

The danger with the "recovery occurs within one year" myth is that it lulls families and professionals into thinking that the client's level of performance at one year is what everyone

is stuck with. While the major brain healing may well have occurred within this time frame, true rehabilitation may just be beginning.

On the other hand, many patients and families who have been told the patient "would recover in a year" interpreted this to mean that no matter how severe the injury, by a year the patient would recover fully. This expectation has set the stage for much bitterness and unnecessary disappointments for patients and their families.

Myth #3: The Concept of Plateau

Closely related to myth number two, this concept says that "recovery" starts after emergence from coma, continues at a gradual upward pace, then slows down, and levels off, so that no more improvement occurs. The visual analogy is a geographic one --a plateau. This myth leads families to despair when rate of change decreases and causes therapists to terminate services when clients stop progressing. There is a tendency to "write off" clients when a first "plateau" has been observed.

It is true that the most dramatic improvement does take place in the earliest stage and is followed by more gradual changes. However, the concept of plateau is dangerous for two reasons.

First, improvement following head injury is characterized by fits, starts, and bursts, often interspersed with periods of apparently little change, or even falling back. Head injured patients are notoriously inconsistent in their progress, at all stages. They may take one step forward, two back, do nothing for awhile, then unexpectedly make a series of gains. When one is preoccupied with watching for plateaus, it becomes easy to disengage from the client whose progress is sputtering.

Second, long "plateaus" can be interrupted years later by energizing environmental events. The appearance of a new, committed counselor, or the influx of social contacts that come from being "forced" to a support group, can uncover functional potential in head injured persons that has lain dormant for years.

Myth #4: The Lourdes Phenomenon

This is often a side effect of subscribing to Myth #1 (the Myth of "Recovery"). The reference is to the town in France (Lourdes) where miraculous cures of illness are reputed to take place. There are many families who firmly believe that some "miracle" will occur after brain injury and return their loved one to normalcy (recovery).

Belief in this myth often takes the form of "doctor hopping" or "program hunting." Families will put the head injured person through every available program or with every available therapist. Despite any tangible signs of improvement, many will continue to believe that if only they could find the right person or right approach, everything would be better.

Of course it is true that **often** head injured patients make significant gains only when hooked up to a competent therapist or top notch program, but that is not what is meant by the myth. Families who believe in this myth cling to the most unrealistic expectations when it is evident to everyone but them that their loved one has limitations which are not going away.

The solution lies not in finding the right "cure", but in helping patients and families become aware of and accepting the limitations and developing new goals and expectations.

Myth #5: Normal IQ

Often, upon request, naive psychologists will examine a head injured person on a

traditional battery of intelligence tests, find that the IQ (the numerical average of the many subtest scores) is in the average range, and then pronounce the client "cognitively recovered", or "capable of functioning intellectually in the average range."

This myth is dangerous because it can seriously misrepresent the client's deficits, and create unrealistic expectations in the minds of others that set the client up for serious failure. The conclusion is a myth for three reasons.

First, an IQ score is a composite of many different scores. An overall IQ score can mask severe variability among performance levels; the person in the "average range of IQ" can be performing in the superior range on some tasks, but be severely impaired on others.

Second, regardless of the variability among the subtests, an "average" IQ score may represent a serious deterioration in intellectual capacity in a client who was premorbidly quite bright, leaving him or her totally incapable of functioning at the level achieved prior to the accident. Persons who experience a drop in IQ from the superior to the average range *do not then function in the average range*. Their scores have dropped because significant cognitive dysfunction is interfering in the consistent application of their intelligence. These breakdowns thrust them far below "average" in real life abilities and functioning, despite the measured IQ.

There is a third reason why "average IQ" is largely irrelevant in the assessment of persons with head injury. Simply put, traditional intelligence tests bear little relationship to the mental processes required for successful everyday functioning. They are composed of brief, highly structured, artificial tasks, that emphasize old learning and overlearned skills.

Head injured persons who can perform quite well on such tests may have such breakdowns in learning, memory, and especially executive functions (planning, organizing, self-monitoring) in the unstructured real world that they are totally unable to function. "Average range IQ" and even higher IQ scores should never be the basis for concluding that a client is cognitively intact, and therefore ready to handle mental stresses of the real world.

Myth #6: The Normal Neurological Evaluation

Just as normal range IQ's should not be mistaken for cognitive normalcy, a normal neurological evaluation -especially late after injury should not be mistaken as meaning that there is no brain dysfunction. As noted above, acute bleeding and contusion of brain tissue may clear up and disappear from brain scans over a period of months and years -even though nerve networks and biochemical balances may still be severely effected.

Also, because head injury is primarily a diffuse brain injury (i.e., involving damage at many scattered locations), it often is not possible to determine a neurological focus of damage as is the case after stroke or tumor (which affect primarily a single area in the brain). Physicians trained in the tradition of "behavioral neurology" are more likely to attend to impairments of higher cortical functions, but many truly dysfunctional head injured persons are misleadingly described as neurologically *normal*.

Myth #7: Malingering

This issue has been dealt with above, and will be only briefly summarized here. Simply put, it is the exception, not the rule, to find clients who are consciously using their deficits to their advantage. The vast majority of head injured patients are extremely frustrated and very eager to get on with their lives.

Unfortunately, it is true that a learned dependency is often established; many head injured persons become so used to others doing for them, that they come to believe that they are incapable and must be dependent, and therefore resist efforts to get them to do more

things on their own. While this process is insidious, common in clients who have been home and inactive for years, and absolutely destructive to the rehabilitation process, it is not malingering.

Learned dependency is by definition *learned* and therefore can be unlearned. Malingerers, however, become more resistant, not less, as they are forced to do more. Most head injured malingerers will probably show evidence of similar behaviors prior to their accident, and should be identified by sophisticated neuropsychological evaluation.

Myth #8: The Disordered Life and the Need for Psychotherapy

Many people who enter traditional psychodynamic psychotherapy do so because they are dissatisfied with their lives. Their dissatisfaction may be due to being unsure of themselves, goals that are not clear, inability to accomplish what they want, unsatisfying relationships, anger or fear, or they are depressed. psychotherapy offers them a chance to explore their feelings and past, uncover and resolve the conflicts that interfere with their lives, vent their frustrations, and get on with their lives.

Unfortunately, although many head injured persons fit the above description and thus get sent into traditional analytic or psychodynamic therapy --they Often get worse, not better, to everyone's dismay. This happens because the disorder in their lives reflects not primarily underlying *psychological* conflicts, but the damage to their brains that has resulted in cognitive and executive dysfunctions. Their lives are disordered because their brains are disordered. "Talking things out" does not solve the problem and may worsen it. This is because traditional therapy removes structure and encourages the spontaneous expression of whatever thoughts and feelings seem most important. Such a process is guaranteed to lead to further disorganization and confusion in a person whose major problem is structuring and organizing the thinking processes, while trying to keep surges of emotion from washing everything away entirely.

When individual "therapy" is a successful adjunct to a rehabilitation program, it is a structuring, supportive, problem-solving approach. This does not mean that head injured persons cannot have mild or severe psychological problems that either result directly from, or exist (usually existed) separately from the results of their injury. They can, and often do. It does mean, however, that the traditional psychodynamic approach seldom offers the head-injured person relief from their disordered life.

The psychotherapist who **specializes** in brain injury must have an appreciation of the impact of brain damage on the patient's capacity to benefit from the process of therapy. Rehabilitation professionals should seek out such specialists if their clients require psychotherapy.

Myth #9: Drugs as Satans and Saviors

The other type of therapy susceptible to mythology is drug therapy --the use of drugs to treat various emotional, behavioral, and even cognitive problems after brain injury. This is a bipolar myth: The equally invalid myth that drugs are always bad (Satans) or the only possible cure (Saviors) for difficult problems after brain injury.

The *Satanic* myth holds that drugs can only do the head injured persons harm and should be avoided at all costs. This myth evolved from a basic truth: Many drugs given to brain injured persons have undesirable cognitive side effects and cause more harm than good. Certain antiseizure medications cause attention and memory problems, and choice of medication often does not reflect this awareness. Minor tranquilizers (such as Valium) which

may calm anxious or tense persons without brain damage, may cause memory problems, poor judgment, and emotional control problems in head injured persons. Major tranquilizers, which organize psychotic thinking and calms agitated behavior in schizophrenics, can have the opposite effect after brain damage. The dampening of the neurotransmitter systems (which helps the schizophrenic) after brain injury decreases cortical functioning, worsens cognitive deficits, leads to more confusion and disorganization, and thus poorer thinking and increased agitation.

Nevertheless, intelligent pharmacology instituted by someone who understands how the damaged brain reacts to drugs can be, when used in moderation, very helpful. Certain seizure medications have fewer cognitive side effects. Drugs that selectively block or enhance very specific neurotransmitter systems have the potential to decrease anxiety, lift depression, and perhaps (although this is still controversial) even enhance certain cognitive functions such as focused attention and memory. Drugs are dangerous, but not Satans.

Nor are they **Saviors**. Occasionally professionals will encounter families who have heard claims made about new drugs that promise all manner of neurological, cognitive, and behavioral improvement, and latch onto such drugs as the "miracle" (see Myth #4) which will cure the problem. Often these are families who have suffered a long time with a difficult head injured family member, and who are having great difficulty coming to terms with the severity and permanence of the disability. No drug known will eliminate the problems of head injury. In general, less is better, but intelligent, selective use can be helpful.

Myth #10: The Rehab Wizard

This is a new myth. That it exists at all is a tribute to positive changes in the system of head injury rehabilitation. The Rehab Wizard practices a craft that goes by many names: cognitive remediation, cognitive rehabilitation, cognitive retraining, and others. The Wizard has a computer (usually an Apple but now maybe an IBM clone) and an armful of software. They load a diskette, wave a magic mouse, and "presto," cognitive changes begin to occur. "Your client is unable to work because of memory deficits? No problem. Send him (or her) to the Wizard for a 10-week course of memory retraining, remediate that deficit, and back to work he'll (or she'll) go."

Such cures don't happen of course. No professional, even one with a terabyte hard drive, and a super fast coprocessor has the wizardry to eliminate cognitive deficits due to damage to the brain. The brain is not a muscle that can, (once damaged) be exercised back to fitness by sheer repetition. Many head injured persons and their families have been tragically let down by the belief that cognitive retraining would be the "answer" to debilitating cognitive and behavioral problems.

Families and professionals must share responsibility for this misconception, but reality is that the competent cognitive remediator, far from being a wizard with special knowledge and tools that others do not have, is a skilled and wily clinician who is willing to use technology, exercises, and guided repetition to help the client in relearning lost skills, learning to focus and sustain attention, learning to identify when cognitive breakdowns occur and how to compensate for them, and how to use new strategies to solve problems when the usual ones don't work.

When understood in this context, cognitive remediation (in the narrow sense of specific, often repetitive tasks) or neuropsychological rehabilitation (in the broader sense of modifying maladaptive behavior and cognition using cognitive and psychological principles) can be an essential part of the rehabilitation process after head injury.

Indeed, it is the increasing awareness that the neuropsychological problems are the most devastating that has led to the admirable attempt to treat cognitive deficits as the focus of, not

just an impediment to, rehabilitation.

We are becoming both more sophisticated and selective in our cognitive interventions, and hopefully scaling down what we explicitly or implicitly promise. The myth of the Rehab Wizard will fade slowly, however, because it would be so good to believe that we could develop a technique to undo the terrible effects of brain damage.

FROM MYTH TO REALITY

The myths aside, there are several concerns that truly are related to improvement following TBI. These include severity of the injury, the victim's pre-injury characteristics, family support, the individual's awareness and acceptance of limitations, the extent and type of rehabilitation, and the long-term support in the individual's home community. A brief discussion of these variables related to outcome follows.

Severity

It is a common principle that the more severe the injury the less improvement can be expected. Severity is typically measured by length of coma (or Post Traumatic Amnesia), and the longer the coma, the more severe the injury. Recent research, however, suggests that while length of coma is related to severity of injury, it appears that the location of the injury is more important. For example, when the frontal lobes of the brain are moderately to severely damaged, regardless of length of coma, significant deficits in executive function are present. These deficits result in the inability to direct and regulate behavior and significantly interfere with returning to pre-injury lifestyles.

Pre-Morbid Characteristics

A number of pre-injury variables are associated with outcome. Those that appear to be most associated with "recovery" are pre-injury intelligence, cognitive abilities, and personality.

Family

The TBI victim's family is critical to improvement in functional abilities. If the family is realistic in its expectations and provide sufficient structure, guidance, and support without fostering dependence, the likelihood of improvement is increased.

Acceptance

The TBI victim's awareness of limitations and his ability to accept the fact that new life goals must be established has been found to be a critical variable, if not the most important variable, associated with successful outcome.

Rehabilitation

The type and extent of rehabilitation following TBI is directly related to improved functional abilities. In years past, rehabilitation was discontinued when the individual was medically stable and could be discharged to his home or a nursing home. Later, rehabilitation was extended and focused on improving the person's physical abilities, e.g., walking and

talking. Today, rehabilitation is available to address the hidden cognitive and emotional deficits that can hinder independent living.

Support

Another critical variable associated with long term recovery is the support available in the victim's home community. Many TBI victims will require life long support to live and work in the community. The extent to which support is available, in terms of supported employment, supervised living, TBI support groups, TBI intervention, and outreach programs, increases the chances of success. In addition, the extent to which government agencies, for example, State Vocational Rehabilitation and Social Security, develop special programs for the TBI victim greatly increases the chances of long term success.

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