The Road to Rehabilitation

Part 3 • Guideposts to Recognition: Cognition, Memory & Brain Injury

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Brain Injury Association of America

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Creating a better future through brain injury prevention, research, education and advocacy.

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Introduction

Cognition and Memory Defined

The dictionary definition of cognition is "the mental process or faculty of knowing, including aspects such as awareness, perception, reasoning, language, memory and judgment." Thus, cognition includes all of the brain's mental input and output, from basic activities like using language and arithmetic during a trip to the grocery store, to complex decisions like selecting between two job offers, to the creativity of writing a poem or song, to being able to understand things from another person's perspective and maintain an emotionally intimate relationship with them.

Part of cognition, memory is much more than simply a passive storage system for knowledge. Memory is a set of active processes that encode information. Memory "packages" the information so that it is easier to remember and can be associated with related items already in memory. Memory also involves storing information, which includes constantly re-arranging what has been stored so that new knowledge is integrated with what is already in storage, and locating and retrieving information as it is needed. For example, cognition assists memory by helping to identify what is important to remember, thereby freeing you of having to recall everything.

A few types of brain injury, such as viral infections deep within the brain, can impair memory without affecting other aspects of cognition. However, in the vast majority of cases, memory impairment is part of a larger cognitive impairment. In fact, many symptoms of brain injury that appear to be memory problems on the surface really are secondary consequences of cognitive deficits. For example, impaired attention and concentration can reduce the amount of information a person takes in, such that even if they have perfect memory, only a portion of the original information will be remembered.

Effects of Brain Injury on Cognition

The brain is a person's organ for thought, emotion and behavior. Injury can disrupt any or all of these brain functions, including the brain's ability to integrate functions and produce complex behavior. As you are reading this pamphlet, you are using your perceptual abilities to see the printed page, your language abilities to make sense of what you see, your memory encoding and

storage so that some of what you read will remain with you afterwards, your concentration to keep all the things going on around you (and inside you) from distracting you, your capacity to form intentions and plans—so that it was you who decided to do this at this time—and your mental flexibility, so that if you smell smoke or hear a baby crying you can re-prioritize your plans and stop reading in order to do something that is more urgent.

Therefore, in asking, "What types of cognitive impairments are associated with brain injury?" The answer is that everything a human being does can be affected by brain injury. While everything can be influenced by brain injury, different diseases and injuries to the brain certainly do produce their own characteristic sets of symptoms. Keep in mind, however, that even though the disease/injury process (i.e., stroke, traumatic brain injury, anoxia, infection, tumor) and the area of the brain that is involved may be known, the ability to predict the types of cognitive and behavioral problems that will result is good, but by no means perfect. The only way to identify reliably the specific impairments of any given person with brain injury is through careful interview and examination of that person and—equally as important— through detailed interviews with the person's loved ones and care providers.

About Terminology

Making sense of all the technical terms for cognition is no easy task. There are hundreds of terms for specific components of cognition, and it is hard for anyone to keep track of them. There are many items that have the same or very similar meanings. Even worse, there are times when the same term means different things to various professionals using it. Some of these differences reflect important scientific and theoretical nuances, but others merely are professional jargon, so called "cogno-babble."

Whatever the reason for becoming confused by technical terms, your best approach simply is to go beyond the term by asking the professional to give you an example grounded in real-life behavior. Thus, if you read a report or are told "Mr. X has deficits in alternating and divided attention, combined with impaired metacognition," you can ask and be told "Mr. X has difficulty keeping track of more than one thing at a time, and he does not observe himself to gauge how well he is doing, so he also is unaware of his problem."

Cognitive Functions

The most useful way to understand the cognitive consequences of brain injury is to know some of the basic categories of cognitive function:

Mental Power

This is the basic, raw energy that supports mental activity. It refers to how much mental work can be performed per unit of time. There is no "good" or "bad" mental power. Rather, power can be used to sustain something simple (i.e., operating a flashlight) or something complex (i.e., operating a personal computer). In both cases, the main issue centers on having enough power on hand. In the cognitive realm, power refers to arousal level (coma being an example of not enough power), to concentration span, to "channel capacity" (how many lines of thought-channels a person can manage simultaneously) and mental stamina.

Power is an important concept in brain injury. The brain areas involved in generating and regulating mental power are very vulnerable to injury, and the majority of persons with moderate to severe brain injury have some impairment in this area. Early on in recovery, the impairments usually are obvious, with the individual with brain injury having difficulty staying awake or focusing his/her thoughts. Months or years later, the residual symptoms may be very subtle, such as the individual having strong mental energy most of the time but showing deficiencies after too little sleep, having a cold or being under stress.

Specific Cognitive Abilities

This refers to a person's stored fund of skills, abilities and knowledge and includes items such as: reading, writing, language comprehension, motor skills and visual-spatial skills. The brain areas that control these functions very frequently are affected by strokes but less often are affected by brain injury. Indeed, when a person with brain injury complains of difficulty in these areas, for example in reading, it is important to assess whether the problem is in the actual skill of reading or whether there is a mental power problem such as poor concentration that is preventing the person from using reading to accomplish a desired result.

Executive Abilities

This is a very large category of cognitive functions and includes abilities such as: anticipating future needs and planning accordingly, setting priorities, regulating impulses and drives, self-awareness and self-correction. In essence, these are the capacities which allow a person to use his/her mental power and specific cognitive abilities to meet social, vocational and internal psychological needs. Imagine you are at a computer that has state-of-the-art software (specific cognitive abilities), a fast processor and lots of memory (mental power); you still need executive abilities to decide what to do, when to do it and what to do first. Further, you must use your executive abilities to decide if you have done well enough to go on to the next task, or if it is okay to play a game on the computer.

The primary cause of impaired executive functions is frontal lobe injury, which is frequent and caused by bruising and/or bleeding in this region of the brain. A number of persons with brain injury have good recovery of their mental power and specific abilities but may be left with executive deficits which limit their capacity to assemble such intact abilities into useful "packages" of behavior. For example, a person with brain injury returned to the rehabilitation hospital for a social visit and was observed on the elevator assisting a person using a wheelchair to get off the elevator. Motor skills, balance and coordination all showed dramatic improvement since discharge, and the person showed excellent visual-spatial skills in manipulating the wheelchair in a crowded elevator.

The problem was that the person in the wheelchair had not been asked if this was the floor he wanted nor was he asked if he wanted help. The help was done skillfully and with vigor, but the results were poor.

The main point of the above discussion is that, in many cases, complaints such as "I can't remember things" or "I can't read anymore" are due to impairments in executive function or mental power. Identifying the underlying cause of a complaint is important because it increases the precision with which we can target therapy.

Cognition and Personality

Cognitive impairments also can affect personality and emotion. For example, having a considerate and empathetic personality requires the ability to think about someone else's needs, feelings and desires and—at the same time—think and experience one's own needs, feelings and desires. Consider a generous, considerate and empathetic person who sustains a brain injury and is left with a deficit in the ability to manage two lines of thought at the same time. This person may appear to have become selfish and self-centered when, in fact, he/she may retain their former considerate personality but not have the cognitive ability to implement their intentions. If you point out an instance of selfishness to the person in the above example, he/she may experience remorse and guilt and truly be puzzled about why they are behaving in ways so uncharacteristic of them.

The experience of having cognitive impairment in itself is frightening and discouraging and often leads to depression and anxiety. While such reactions can be a source of great pain and despair for the person and his/her loved ones, it is important to keep in mind that they also are positive signs, indicating that the person now has the cognitive ability to be aware of his/her situation. A common scenario is for the person to be in a good mood early in recovery when self-awareness still is very impaired; and then as self-awareness improves, the individual enters a phase of depression. A competent cognitive treatment program will pay close attention to such emotional issues and will have the capacity to provide psychological and psychiatric treatment as needed.

Course of Cognitive Deficits

In most cases, cognitive deficits are most severe immediately following injury and show an improving course thereafter. A commonly used rule of thumb is that recovery is rapid in the six months to one year after emerging from coma, and that it continues at a slower pace for the next one to three years. However, there are many exceptions; not everyone's course of recovery runs smoothly or follows this pattern.

Sometimes, one cognitive deficit can hide other cognitive deficits, and it is not until the first deficiency improves that the other deficits can be seen. For example, impaired alertness and mental power can result in a person being

lethargic and not exhibiting much behavior. As mental stamina improves, the amount of behavior also increases. For the first time, it becomes possible to see that the person has problems with impulse control and logical reasoning. This can be discouraging particularly to individuals most emotionally involved.

Another factor that influences the course of cognitive impairment is the person's environment. Often, families will note that their loved one's cognitive deficits "worsened" upon leaving the hospital. Usually, there has been no real deterioration. Rather, the hospital was a simple environment where a person was told what to do, when to do it, when to stop doing it, what he/she was doing well and what needed improvement. A person with impaired executive abilities can function quite well in such a hospital environment. At home, the person wakes up the next morning and has severe problems simply deciding what to do next. Thus, cognitive deficits can be hidden by simple and supportive environments, and later unmasked by complex and challenging environments.

Finally, when a person is showing an unstable, flat or negative course of cognitive recovery and it is not caused by identifiable factors such as those just mentioned, medical complications should be suspected and evaluated.

Assessment and Diagnosis of Cognitive Deficits

Assessment serves many purposes. It is used to: (1) identify areas of cognitive impairment and cognitive strength, (2) monitor improvement or deterioration, (3) design remediation programs, (4) evaluate the outcomes of treatments, (5) predict future vocational and educational capacity and (6) document symptoms for legal, insurance and educational issues, as well as for purposes of public benefit eligibility (i.e., Medicaid and Social Security).

During the recovery process, cognitive deficits not only change in severity but—as noted previously—different impairments may appear as others disappear. This means that the person's status cannot be captured by any single assessment. Instead, many assessments must be conducted throughout the recovery period to capture the dynamic nature of improvement.

Timing of Assessment

Early on in recovery, individuals typically are confused, disoriented, agitated and impulsive. Conversely, in some cases, individuals may be lethargic, apathetic, somnolent and uninterested. During this phase, it is pointless to engage in detailed, lengthy and expensive cognitive assessments. Deficits such as agitation or apathy prevent a person with brain injury from participating meaningfully and reliably in these evaluations. Moreover, at this phase, people often change so rapidly that the results of the assessment can be outdated by the time the report appears on a medical chart. Most useful at this stage are simple and brief rating scales of amnesia, orientation and behavior. Legal needs for careful documentation of status can be met via these rating scales and by videotaping the person.

After brain injury, most individuals recover sufficiently to participate meaningfully in cognitive assessment. Once at this stage, it is possible to begin identifying the specific cognitive abilities that are damaged, as well as those that are intact. Identifying cognitive strengths is just as important as finding the deficits, as it is the areas of strength that will be the foundation of recovery.

At this point, the future legal needs of the person with brain injury also should be considered. Cognitive assessment provides information useful for guardianship and competency decisions and for documenting eligibility for disability insurance and other compensation. If legal proceedings are anticipated, it is very important that at least one of the assessments use formal, standardized neuropsychological tests that have a known record of acceptance by the courts. Keep in mind that the legal proceedings may not take place for many years, by which time the person with brain injury can look dramatically better but still have deficits which are difficult to measure. It is much easier to make a convincing argument that such subtle deficits are due to the brain injury if there is data demonstrating that the same deficits were present in a not so subtle form at an earlier time.

Individuals in professions which offer treatment for cognitive impairments (i.e., neuropsychology, occupational therapy and speech and language pathology) use tests specially designed to identify cognitive deficits, and incorporate this information into the treatment planning process. However, tests are only part of a good assessment. Equally important is measurement of the person's real-life functioning (i.e., "He has a great IQ, but can he tie his shoelaces?"), which includes the observations and perceptions of family members and caregivers.

The functional assessment especially is important for identifying impairments in executive functions (i.e., "If left alone, does he tie his shoelaces?"). The evaluation also should include learning as much as possible about the person's pre-injury level of function. School records, work samples and test scores from before the injury help therapists to identify what is "normal" for that particular person.

The cognitive assessment always should be paired with an assessment of the emotional state and the reactions to how brain injury has affected the person's life, including hopes, dreams and aspirations. If left untreated, emotional reactions can develop into full blown psychological disorders that may become as disabling as the cognitive deficits. Moreover, depression and anxiety by themselves can degrade cognitive performance.

Recovery

The mechanisms underlying recovery of cognitive function are not understood completely. It is known that for weeks and possibly months after injury there is actual healing occurring within the brain. Nerve cells that have died do not heal or regenerate, but injured nerve cells can heal and return to active function. Also, some of the generalized effects of injury, such as swelling, gradually subside and permit surviving nerve cells to resume functioning. In addition to healing, there probably is a component of the brain reorganizing its circuits so that the remaining healthy nerve cells take over some of the functions of the damaged cells, a process termed *reorganization of function*.

Along with biological mechanisms of recovery, there are behavioral and cognitive mechanisms which fall into two categories—*learning* and *compensation*. Damaged nervous systems are capable of learning new behaviors. The learning may be slower post-injury, less complete and with a higher error rate, but there is no question that some capacity for new learning remains, in most cases. However, the new learning may take many years of recovery, long after the biological healing processes are over.

Compensation refers to techniques where assistive devices or procedures are used to overcome impairments that cannot be modified. For example, a wheelchair is a compensatory device. In a case in which exercises will not result in a person's being able to walk, the wheelchair provides mobility. These assistive techniques take many forms. For example, compensatory environments are settings where complexity, novelty or supervision intensity

are controlled so as not to exceed the person's cognitive capacity. The degree to which performance can be enhanced by a supportively-structured environment is remarkable. Helpful devices exist that help a person perform cognitive functions, such as memory logbooks, electronic watches that emit a signal for the person to perform some activity that they would not remember (i.e., taking scheduled doses of medicine) and computer software that can assist a person to organize and manage complex information.

Treatment

Treatment of cognitive disorders takes several forms, depending upon the problem:

Mental Power

Problems such as poor mental stamina or poor concentration often respond well to fatigue management strategies. The person's sleep-wake cycle is analyzed to determine if daytime alertness can be improved. Many persons with brain injury have disturbed sleep-wake cycles, and some have true sleep disorders. Such disturbances can be corrected by behavioral therapies to improve sleep hygiene and remove impediments to sleep. Medical treatments also may be helpful. In some cases, the treatment is as simple as scheduling a brief nap. In addition, fatigue management includes working with the person to find the optimum balance between work and rest. Overwork or exceeding one's limits may backfire badly in someone who has problems with mental stamina. It may take many days to restore a person to the former level of function.

Problems with alertness, attention and concentration also can be treated medically. The use of medicines to improve cognitive function following brain injury is relatively new, but there is no longer any question that some persons obtain meaningful benefit. It is best to identify a physician experienced in this area and then work closely with him/her.

Specific Cognitive Abilities

Impairment-specific interventions focus directly on the area of deficit, such as when an individual has memory problems and is given memory training. Impairment-specific interventions for speech/language problems, visual-spatial abilities and attention have shown some record of success. However, memory training has shown mostly disappointing results, in contrast to memory treatments based on compensatory devices such as logbooks, which have shown good success.

Executive Deficits

Executive deficits are best treated through programs that utilize real-life performance as the treatment focus. The person with brain injury may be observed within the community or work setting and therapy occurs as the person is performing. An example of this is <u>job-coaching</u>. In this situation, the person takes a job and the therapist attends the job site and assists and trains as needed. Executive deficits also can be treated in individual therapy, though this is usually in addition to and not instead of treatment in real-life situations.

Comprehensive brain injury rehabilitation programs provide integrated treatment of all three categories of deficits. The mission of these programs is that of helping the person with brain injury repair his/her overall level of function and quality of life. Such treatment has a broad focus that includes: (1) interpersonal and social skills, (2) work and school behaviors such as completing assignments and being punctual, (3) emotional adjustment and self-acceptance and (4) using cognitive skills in real-life settings. Most studies of comprehensive programs have shown moderately positive results, though even the most successful programs do not help everyone.

Rehabilitation clinicians frequently encounter requests from persons with brain injury and their loved ones for more treatment on the assumption that if a given amount of treatment is good, then more would be better. Very often, this is not correct. In many cases, the most important factor is that a reasonable amount of treatment be provided for a very long time. Because of the need for long periods of treatment, it is important to maintain motivation and interest and not burn everyone out by a heroic sprint. Recovery from brain injury is a long distance run.

About the Author...

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For additional information about dealing with post-traumatic headaches and brain injury, contact BIA's Family Helpline at (800) 444-6443 or familyhelpline@biausa.org. Or visit BIA's award-winning web site at: www.biausa.org.

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For the individual with brain injury and his/her circle of support (i.e., family members, significant others, friends and co-workers) brain injury is a complex and often tumultuous journey. Although there are broad issues affecting ALL individuals with brain injury, both the road to rehabilitation and the outcome experienced by each individual are unique. In this series of brochures, BIA seeks to educate individuals and organizations about rehabilitation after brain injury. Some individuals with brain injury may face challenges in all of these areas, while others may experience problems with just a few of them. Regardless, the information in these brochures is crucial to provide those affected by brain injury, as well as the individuals and organizations treating them, with a basic understanding of the complex challenges following brain injury. For additional information about any of the topics covered in The Road to Rehabilitation Series, contact BIA's tollfree Family Helpline at (800) 444-6443 or visit their web site at www.biausa.org.