



Rehabilitation of Mind, Motivation, and Identity after Traumatic Brain Injury

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Mind and Meaning

From the time of our arrival in the world, our actions create ever widening ripples spreading out in all directions like those from stones cast into a pond, touching people and shaping events around us. "Ripples" from the actions of people and events around us touch us, and in turn change us, sometimes slightly, sometimes dramatically. Throughout our lifetimes we thus both create and are created by our experiences.

With our ability to remember and evaluate many of these points of contact, the continual collisions of action and reaction between ourselves and others that would otherwise simply happen and disappear forever, are transformed by reason and memory into permanent webs of association with other people, things, and events that connect our past with our present and our future.

Obsessively mind-full are we, moving about in our virtual mental reality sometimes at will and sometimes against it, in day and night dreams, in pleasurable and painful reminiscences, in dread and delight-filled future expectations, and in solitary, purposeful reflection over our experiences, over our aspirations and our options for achieving them. Back and forth across our ever-expanding and ever more elaborate web of association, suspended by past and present associations, and even by associations with an anticipated future, we traverse the filaments of mind in search of meaning in our lives.

As these webs develop, we find ourselves less and less fully present in objective reality, less "in the moment." By the time we are adults we travel within the subjective, virtual world of mind incessantly, like butterflies lighting for mere seconds before mentally flitting to other places and to other times.

Consciousness and Identity

Understanding and insight are the crowning achievements of mind, in particular, understanding who we are, our identity. "Consciousness" is the word we reserve for the capacity if not the guarantee to know, to understand our lives and ourselves.

Human consciousness is so much more than an alternative to sleep. Human consciousness--and as far as we know only *human* consciousness—includes self-awareness that can only emerge in the context of our vast web of association and meaning that we augment throughout our lifetimes. We reflect upon and gain insight based on what has gone before, and foresight into how things might be in the future, based upon present and past experience.

We develop an image of who "we" are, our self-concept. We develop ideas, attitudes, and beliefs about ourselves, about our abilities and limitations, about whether we are coordinated, likeable, good, intelligent, significant, and worthy. Ultimately, we develop attitudes and beliefs over whether our lives as a whole are significant and worthwhile.

Brain Injury

Because the seat of consciousness is the brain, brain injury often upsets the web of recollection and meaning. As a result, our previous ability to interpret our lives, to navigate toward our futures, and to conceptualize our identity, purpose, and value as a person may be impaired. Damage to our ability to call forth an experiential context for our present situation may leave us feeling relatively more alone and less able to grasp it, and perhaps fearful as a result. Judgment and insight may become more difficult and thinking ahead more challenging. In some cases an individual may be all but "trapped in the moment," living life impulsively, with little or no appreciation of the consequences of actions that fuller consciousness once provided, too often frustrated by a world that seems filled with nothing but obstacles.

Rehabilitation and Hope

It is in this or some similar state that many individuals with a brain injury enter into the rehabilitation process. Doctors and therapists offer help in the form of therapies of various kinds, to restore function or to compensate for difficulty with movement, thought, emotion, behavior and communication.

But before meaningful treatment can begin, a therapeutic alliance must be forged between patient and doctor (or therapist) based on agreement about what needs fixing and how to go about it. Hope is essential for the bond between patient and doctor/therapist to exist. But the person who has been injured may have difficulty

feeling hopeful and thus in creating a satisfactory alliance with doctors and therapists.

Hope depends upon belief that meaningful recovery is possible. It involves being able to recall overcoming obstacles in the past, that success in the past required persistence and struggle but that these ultimately produced success. Hope also depends upon seeing how you are going to get from "A" to "B." Think of the great feeling you get when you are lost in an unfamiliar town and you finally find someone who gives you clear directions and you come away with a mental map you know you can follow. That is hope!

And hope depends upon being able to hold the vision of an ultimate goal in mind and to conjure it forth when you most need it. How would the body builder, aspiring scholar, or athlete persist throughout all the difficult hours, days, and years of essential training if they could not conjure up a vision of rippling muscles, a diploma and new job possibilities, or gold medals, in order to sustain them as they confront the last set of bench presses, another all-nighter for another big test, or getting up before sunrise for yet another grueling practice session? This conjuring is a mental act. It is a feat of the mind, a consequence of that intricate web of association that brain injury disrupts, at least temporarily, sometimes permanently.

Motivation Disability

Only intact minds can manufacture hope, the basis of motivation, and only with tremendous and constant self-reminding about what is to be gained through persistence and what is to be lost through lack of it, only with a certain level of self-confidence to start with, and only with a lot of support from loved ones. A brain injury may make recollection of past success difficult or impossible to recall, connections between present effort and future gain difficult or impossible to conceptualize, especially when these associations are most needed--when the going gets rough. Self-reminding requires tremendous mental dynamism that is not typical of an injured brain and self-confidence may be hard to come by when almost every daily activity presents so much difficulty. And the fact is, that many individuals who have had a brain injury lack support of friends, and family.

It is no wonder that for all of these reasons some individuals who have suffered brain injury lose motivation or never appear to have it, and may withdraw from recommended therapies and be labeled "non compliant." It is a tragic irony when a person is discharged from treatment for exhibiting a natural consequence of their injury--tragic, but inevitable in many cases, considering that cognitive rehabilitation is not a covered service by most insurance.

Even though the signature disability of brain injury is cognitive disability--damage to the processes underlying mind, consciousness, motivation, and our very

identity—insurance companies persist in denying claims for cognitive therapies, and in limiting benefits for any kind of treatment to a matter of weeks, for a condition that will require years to overcome.

One excuse for this state of affairs is that cognitive rehabilitation has no "scientific basis." Had physical therapy been so limited, it is doubtful any scientific basis would have developed for it, just as it is unlikely we would have carts, had God made neither horses nor oxen to pull them.

The Role of "Alternative" Therapies

Music, art, writing, theatre, dance--these may appear to be activities a person with brain injury might perhaps aspire to *after* rehabilitation rather than essential, *first* rehabilitation activities. But observing that brain injury may impair an individual's ability to participate in traditional therapies has forced a reconsideration of these and other activities once considered exclusively "alternative," as potential *primary* therapies.

There is an intuitive correctness to the involvement of artists in brain injury rehabilitation. Brain injury disrupts connection, meaning, wholeness. An artist is a creator of connections, of meaning, and of wholeness. The eyes, ears, and other senses of the artist are uniquely developed so that artists see connections and meaning where others see none. So real and so compelling are their perceptions of the world that they feel compelled to re-create them to help the rest of us see what is so vividly apparent to them.

Artists will try anything, use any means, to try to re-create meaning in some concrete form, including brushing colored goo onto blank canvasses, penciling odd characters onto score sheets to make specific sounds come from musical instruments, using word processors and paper, armatures, clay, kilns, intricately folded pieces of paper, stages, actors, sets, props, and on and on and on.

An artist entering a medical setting introduces an immediate and unsettling transformation. Where others see "patients," catastrophe and loss, artists see viable, unmistakably whole, fellow artists. Seeing oneself reflected so certainly in such eyes causes insecurity and self-doubt to dissipate like mist before a hurricane. Words like "patient," "disability," and "therapy" are suddenly out of place. Loss, pain, and fear are transformed from withering adversaries to formidable if not entirely welcome allies, from agents of anguish to subjects of creativity, essential fodder for sublime, witty, and dark, triumphant, and whimsical works of art.

The artist's unwavering, total regard for each person's creative power, and their encouragement to fearlessly explore every and any feeling or idea, inevitably leads to the re-discovery of other emotions, including confidence, pride,

determination, and yes, hope. And for reasons we do not really understand, brain injury often unleashes astounding creativity in individuals who may never have engaged in creative activities prior to being injured. The recovery of identity, purpose, and pride vaults forward when activities in the studio become exhibitions, performances, CDs, movies, and books for public consumption.

Programs that explore the use of fine and performing arts quickly discover that they are core, indispensable therapies rather than therapeutic alternatives. The arts can engage individuals who may have been unengageable previously, to develop attention, persistence, cognitive endurance, visual perception, motor skills, planning, problem solving, reasoning, and judgment, and, may lead the way, may lead significant numbers of individuals with brain injury, to participate for the first time in the more traditional therapies such as occupational, physical, psychological, and speech therapies.

It is not whether these and other "alternative therapies" work, but rather how well, with whom, and under what conditions. These are answers that must wait, unfortunately, until governments or citizens become sufficiently outraged at the intransigence of the insurance systems they pay for to compel them to at least begin to provide some reasonable coverage for cognitive therapies.

Other "Alternative" Therapies

The fine and performing arts may succeed where more traditional therapies may initially fail for a number of reasons. An art activity may be more immediately satisfying and fun for some. A person can participate without the stigma associated with therapies that require more open acknowledgement of disability, because even though they are therapeutic, the fine and performing arts are not "therapies" at all. Someone who fails in a simple reasoning task provided by a speech-language pathologist is more likely to be embarrassed (even if no less frustrated) than someone having difficulty painting a flower vase presented by an artist.

Other "alternative" therapies may succeed for similar reasons. Activities such as cooking, cleaning, working a cash register, dealing cards, calling a bingo game, making jewelry or greeting cards to sell, waiting on customers, serving on a planning committee, and others, may offer a high degree of immediate satisfaction, may feel familiar and comforting, and, if appropriate support is given so that the person can succeed at these activities, allow the person to feel important and "normal." These are activities that are offered by occupational therapists, recreational therapists, special educators, and vocational therapists, and again, activities that are poorly, if at all, reimbursed.

Avocational Rehabilitation

Recovery from brain injury can only be considered complete when an individual has recovered some life activity, and associated family or community role, that is personally meaningful and that brings a sense of pride and purpose. With sufficient support and encouragement it is possible to promote the discovery of some activity about which a person feels excitement, passion, and joy. The culmination of this phase of the recovery journey places persons with brain injury squarely onto the same path with many people who are not brained-injured, a path where we seek to develop our gifts, and through them, to connect with others.

Brain injury rehabilitation must offer opportunities for developing such meaningful and central life activities. Vocational rehabilitation--another grossly under funded area of rehabilitation--focuses on return to work. But the workplace may or may not offer these opportunities. The concept of "avocational rehabilitation" is broader, it includes any activity an individual feels is important enough to do as a central life activity, and that typically brings them into consistent contact with others, whether or not compensated.

Without such an activity, the core of our lives is empty and we lack a reason to get up, to go out, and we miss out on many of the best opportunities to meet others with whom we might identify and forge close bonds of friendship and thus develop a network of social support. For the lack of such a core avocational activity, many individuals who achieve fair to complete physical independence after brain injury remain highly vulnerable to social isolation, to depression, and to a reality-based sense of futility.

One of the challenges to avocational rehabilitation, in addition to lack of consistent funding, is a lack of appreciation for the importance of avocation in our society. We are increasingly a society beset by workaholism that values less and less life outside of work. Consequently, it has become easier and easier to devalue those who cannot work and less and less likely for citizens and for governments within such societies to see the importance of this aspect of rehabilitation.

Summary

Our minds are our personal road maps of reality, a map that continues to develop throughout our lives unless disrupted by brain injury. In the aftermath of injury to the brain, our ability to mentally "see" how past experience should guide present action to lead to desired future consequences may become impaired. Motivation disability and loss of identity are common consequences of this cognitive impairment, which is the signature impairment of brain injury. Although our system of healthcare frequently fails to address cognitive impairment, there are

many options for helping individuals become whole. Many of these options begin with what have been referred to as "alternative" therapies such as fine and performing arts, recreational and avocational therapies, therapies that we believe over time will find their way to the center of rehabilitation programs for individuals who have experienced brain injury, especially those treating individuals in the moderate to severe range. Reimbursement for these types of treatments, and for brain injury generally, remains a problem. Research is also lacking that clearly establishes the best way to use these approaches. However, those who have begun to explore the utility of these approaches quickly realize that the question for research is *how* to use them rather than whether to use them at all.

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