

A Triad of Issues in TBI Rehabilitation--Past and Present

A Triad of Topics

One of the distinctions of old age is that others expect us to have become somewhat of a depository of past events. So when honored with an invitation to give this lecture, I was also asked to provide some neuropsychological history. Tracing the history of neuropsychology would have required a several hours long lecture while straining my limited resources and probably boring me, if not you. Instead, I have chosen to remind myself and you of the history of three issues that I consider to be at the heart of what makes TBI rehabilitation effective: appreciation of the dysexecutive syndrome, the problem of awareness of the problem, and patient and program evaluation.

But first--keeping to my assignment as historian--I want to remind you that

Some major contributors

TBI rehabilitation is a multinational enterprise. Many individuals from many different countries have made significant contributions to TBI rehabilitation as we know it today. Foremost among them are the great Russian behavioral neurologist Aleksandr Romanoff Luria and his Danish protégée, Anne-Lise Christensen. As a young psychologist, Yehuda Ben-Yishay worked with head injured soldiers in Israel and then brought his skills and his passion for TBI rehabilitation to New York. Jean-Luc Truelle and Jean-Michel Mazaux and his coworkers in France have added knowledge and enhanced effectiveness of TBI rehabilitation. The Australian neuropsychologists, Jennie Ponsford and Robyn Tate, with their teams, have

developed TBI programs with a strong research emphasis. Barbara Wilson and David Neil Brooks in the UK; Keith Cicerone in New Jersey, George Prigatano in Arizona, and Jim Malec in Indiana continue to make unique contributions that now

Anne-Lise & Yehuda etc.

are incorporated into the best rehabilitation practices. I also want to salute my mentor, Joseph Wepman, a clinical psychologist during WWII, who worked with head injured aphasic soldiers before coming on the faculty of the University of Chicago. And these are only some of the many thoughtful and dedicated men and women who have given TBI rehabilitation its now sturdy foundation.

It is ironic that we owe so much of our early knowledge about the behavioral consequences of brain injuries and rehabilitation possibilities to war. The most basic information about brain function came from bullet wounds--in the first World War especially, but also the second. In those days, bullets tended to make discrete lesions, knocking out very specific parts of the brain which permitted exquisite studies relating cognitive and behavioral disorders to brain structure.

Larry's language problems

Larry's brain

Today's soldier-survivors no longer present the well-defined wounds of yesteryear; blast injuries and broad ranging damage due to more powerful ammunition present a different set of rehabilitation challenges.

Now in relative peacetime, MVA's are by far the chief TBI--creating culprits. Thus most TBI rehabilitation here and throughout the world focuses on these

survivors. Some of the best programs have been developed in Australia where a forward-thinking insurance industry realized some time ago that good rehabilitation is far cheaper than long-term support of socially dependent persons. France, too, has a number of interesting programs as a result of a national funding program which enables each Department--their geographically defined administrative units-- to develop rehabilitation projects appropriate for their communities.

We have only very recently become aware of the rehabilitation challenges posed by injuries incurred in sports. Previously--and still in many places--these injuries have been considered either nonexistent or too mild for serious attention. At last, sports injuries are recognized in many centers with treatment programs in various stages of development. Like much of TBI rehabilitation, it is a learn-as-you-go endeavor. With better knowledge of the brain dysfunctions and sensory disturbances due to sports concussions TBI rehabilitation enables concussed youngsters not only to return to school, but to graduate from high school and college despite having sustained significant injuries.

As you can see, TBI rehabilitation's history covers a lot of ground. For the rest, I will limit my remarks to the three issues mentioned earlier, issues that are essential to effective application of TBI rehabilitation principles and techniques: appreciation of the importance of executive functions; the problem of unawareness of the problem; and some issues in outcome evaluation.

Executive functions

When a blow to the head produces more than a mild concussion, both MVAs and sports injuries tend to involve frontal structures which dispose to executive function disorders. This statement does not denigrate concussive injuries which almost always occur in MVA's and sports TBIs and thereby compound the other problems resulting from the damage to the brain. Mild concussions, by themselves, have their own more or less serious consequences, the seriousness likely to increase with the number of blows the head has received both recently and over time. The problems associated with a single mild concussion rarely require full-bore rehabilitation--they are a topic all to themselves and will not be dealt with here. Frontal lobe injuries, on the other hand, typically involve the executive functions making social and emotional readaptations following the injury a difficult process that can be greatly helped by good rehabilitation.

However, early TBI research with wounded soldiers focussed on disordered cognitive functions, especially memory and attention. Even a most acute observer of his soldier patients as Kurt Goldstein interpreted their ineffective behavior as cognitive disorders due to concrete thinking and loss of abstract reasoning without identifying their executive impairments. Emotional disturbances were also acknowledged, especially those that were disruptive, such as negativism, anger outbursts, and hypersexuality.

Executive functions list

Between the two world wars and for some time after the second one, many persons working with TBI patients tended to overlook or not be aware of compromises in the more subtle and seriously handicapping deficits--impairments in the abilities to initiate activity; to make realistic plans; to maintain planned activity; to keep plans and goals in mind and change them appropriately as circumstances change; to self-monitor and self-correct ongoing actions; and to be sensitive to the emotional state, needs, and activities of others. In short, these are the abilities that are absolutely essential for full social independence, yet for many years they were not part of the typical rehabilitation program.

Executive functions can be overlooked

I believe there are a number of reasons for this lack of awareness of these very central problems. Not least of these is that TBI patients in rehabilitation settings had been and still may be passive recipients of their treatments. These treatments often consisted of therapies that had been developed for and proven successful with stroke patients with left-sided lesions, persons who tend to be acutely aware of their disabilities.

Moreover, rehabilitation hospital or clinic programs can be highly structured such that almost all activities are planned and organized leaving little room for anyone to observe whether the patients can plan or organize their time, activities, etc. In many live-in programs, patients are awakened at a set hour; if they have physical injuries someone may bathe and dress them; meals are planned and prepared by others and served on schedule; training, and lessons, and therapies are

planned and programmed by others. Even leisure activities may be arranged by staff. These patients have little opportunity to act on their own and clinicians have little opportunity to observe how their patients behave when on their own.

Another reason for this not uncommon blind spot in behavioral observations is due to our very natural assumption that executive functioning is integral to human nature and not separable from being human. Two-month old infants will spontaneously follow a bright object--or their mother--with their eyes; at four or five months they spontaneously reach out for object or mother demonstrating self-initiating and goal-seeking behavior; at eight or nine months they see what they want and eagerly crawl toward it. This is behavior that, for most people, seems to be ingrained in us, an indelible part of the human repertoire. Given these species-wide experiences, learning to appreciate that drive and goal-seeking behavior may be compromised due to a brain injury does not come easily.

Further, executive dysfunction can be subtle. Executive activity involves the "how", not the "what" of behavior. Tests of memory and attention, arithmetic ability and reading comprehension, for example, all examine what a person can do. Unless administered by an experienced and knowledgeable examiner, all that will come from a mental ability examination--what some refer to as an "intelligence" test--will be test scores with no indication of how the examinee passed--or more important, for examining executive functions--how that person failed.

Executive dysfunction: chiropract

50 yo medical specialist with a doctorate; MVA- "hit the headrest hard" on the back of his head with no LOC:

Background information-superior; arranging cartoon pictures-high average;
list learning-within normal limits

Cowat-L-library, logs, linguine, Lincoln, links, liturgy, latitude, ladder, lace:
 $\Sigma = 8 + 1E$; predicted $\Sigma = 15$

Picture Completion- Σ failed=8/25, score-low in the average ability range
>tipped pitcher half-filled with water at its spout, glass below half-filled with water:
"nobody holding the pitcher"
>leaf lacking a vein: "tree"
>fireplace with fire but no smoke from chimney: "house"

Mention personality changes--silliness, crudeness, diminished sensitivity

Those of you who lived in Oregon twenty years ago paid out a considerable amount of money for the supposed rehabilitation of a logger who was 32 years old when I saw him. Our state's Vocational Rehabilitation program had been training him without success for six years. They considered him to be highly motivated and worthy of continued training since he repeatedly said, "I want to work, I want to work." Finally someone suggested that the head injury he had sustained from a 30 foot fall from a tree might have something to do with his inability to profit from their programs, despite his apparent eagerness to return to gainful employment. At last he was referred for neuropsychological assessment. He scored at best in the low average ability range on the usual mental ability tests, but many people with low average abilities maintain themselves very well in the working world.

However, among other evidence of executive impairment, this man could not find his way out of a maze. Disability retirement was recommended.

logger's maze

exec functions: rehab goals

Today, the best programs for persons with TBI in the moderate to severe impairment ranges include focussed retraining of executive dysfunction along with the specific cognitive limitations associated with the injury. These programs are also suited for those whose injuries technically fall into the mild category but involve focal frontal damage. Thus, central to all the work done with these persons is helping them to achieve realistic awareness of their disabilities--and their strengths; to acquire mastery over necessary skills; to enhance their abilities for self-monitoring, self-correction, and self-control; and to make peace with their limitations [I don't use the term "acceptance"] with the goal of reestablishing their new identity and--in so far as possible--learning to like it. With these goals, many rehabilitation programs help persons with TBI to live comfortably and appropriately in their communities, to participate in family and social life, and return to unfinished education or to productive work.

Still, for some persons with diagnoses of moderate TBI and many whose injuries were severe, an executive function disorder may continue to be a central disability despite the best rehabilitation efforts.

When rehab has limits

These are the survivors whose injuries lesioned or disconnected frontal lobe areas necessary for self-awareness, motivation, and maintaining self-directed drive and behavioral controls. Yet many of these survivors retain premorbid skills or the ability to learn new ones. They too want and need productive activity, social

stimulation, dignity, and affection--but may be unable to make these connections independently. To meet their very human needs, structure and direction must come from outside. In the best solutions, many can thrive in structured living and working environments enabling them to perform at their best with good support and social stimulation. Unhappily, in the richest country in the world, too many are left to the care of overburdened families who lack the understanding, time, and finances needed for effective care of their loved ones. Others end up in the street, in jails for loitering or trespassing or being a nuisance, or in retirement homes to spend their often young lives with elderly stroke patients and demented persons. If you must get a severe head injury, first make sure you have citizenship in a European or British Commonwealth country.

awareness problem problem

The "awareness" problem problem

It is not uncommon for persons working with TBI patients to use the label "in denial" to account for a patient's diminished capacity for self-awareness and family members' naiveté. At the outset I acknowledge that some people are "in denial" about their problems--most usually persons with psychiatric disorders or unpleasant personality characteristics. However, the term is much less often appropriate when applied to persons with TBI or their family members.

Some individuals, especially those with frontal lobe lesions and injuries to the right hemisphere, may develop a condition--anosagnosia--such that their awareness of their disabilities is diminished or even nonexistent. Labelling this condition

"denial" is usually due to a grave misunderstanding of the problem. Such misunderstanding greatly limits rehabilitation candidates' prospects as effective rehabilitation requires them to know their problems and identify realistic goals, as only then can they actively cooperate in the rehabilitation process.

A 48-year-old physician was found unconscious after his car ran off the road into a tree. A year later he applied for return of his license to practice medicine. At this time this previously divorced man was living with his mother on whom he had become semi-dependent. He had lost sight in his right eye and was aware that left eye vision had been compromised, but interpreted the problem as tunnel vision. To remedy this, he had hung a little telescopic device such as watch-makers wear, on the left lens. He was unaware that he had left-sided visuospatial inattention such that he had very limited awareness of what took place in the left side of his space and did not appreciate his incompetence for medical practice.

Cognitive competency per se was not the issue: He scored in the very superior range (top 1%ile) on oral arithmetic and vocabulary tests, at superior levels (top 5%ile) on background information and a variety of verbal skill and reasoning tests; both verbal and visual learning were within normal limits. The inattention problem became apparent on visually presented tests; reasoning errors and executive deficits associated with frontal lobe involvement appeared throughout the examination.

MD 1 yr post MVA

Exs. Q: Why should the state require people in some professions to get a license?

A: So they can get a fee

Q: How are a dog and a lion alike?

A: both have hairy coats, walk on four legs

Copied the printed word "bicycle" as Bicyclicle

COWAT C Words: cold, coal, coat, cloak, cash, clean, counter, count, sequin, cost Σ Expected=15; performance level defective (in lowest 3%)

brief hx of anosognosia-1

Anosognosia had been recognized and described since the late 1890s as a condition exhibited mainly by right hemisphere stroke patients. For decades, Yehuda Ben-Yishay, George Prigatano, and other observant neuropsychologists

working with TBI patients, have been calling attention to this problem in articles, lectures, and workshops. For example, in the 1980s Anne-Lise Christensen, knowing that many of the trainees in her program with moderate to severe TBIs lacked useful awareness of their disabilities, posted their brain scan pictures at each individual's work station so there would be no doubt about the source of the life changes they had experienced. lectures, and workshops.

Brief hx of anosognosia-2

Most recently, Prigatano edited a book, Anosognosia, a must-read for rehabilitation workers who may be unaware of the problem of unawareness. In knowledgeable rehabilitation settings, TBI patients with this condition are no longer likely to be accused of being "in denial."

Importance of awareness for rehab

Today, whether referred to as "unawareness" or "agnosognosia," for some persons with TBI it may be the central issue to address for effective rehabilitation to even begin. For many of them it will be one of many issues, but always a necessary one for those rehabilitation candidates who lack realistic awareness of their disabilities and prospects. "Only awareness and self-understanding can and will motivate the individual to engage--wholeheartedly--in the sustained process of rehabilitation." Ben-Yishay & Diller, 2010.

For many rehabilitation programs today, unawareness of the problem of unawareness is no longer a problem. However, "denial of disability" or "being in denial" continue to be terms of disapproval and disparagement that may be applied

to family members. Many experienced clinicians--physicians, nurses, and yes, psychologists too, and others who work with TBI patients--readily recognize the signs and symptoms of subtle frontal lobe disorders, the executive disorders-- that can put a person's life not just on hold, but well in reverse. With experience, these signs and symptoms become so obvious that, when not perceived or appreciated by family members, clinicians may assume that these well-meaning people are pretending to themselves and others that TBI has not changed the patient; i.e., that they are "in denial."

"Denial" & the family

Lack of appreciation of executive function disorders by naive observers, such as family members, can be accounted for in several ways. Perhaps the most important of these is everybody's tendency to perceive the people they know through the veil of past experience--not perception, but apperception. A common example of this is the tendency to see close family and friends known from their youth as younger than they are, so that a current photograph with the droops and wrinkles of older age may seem surprisingly strange.

In the same way, we build up expectations of the people we know--of their vigor, moods, special skills, and so on. After a TBI has altered aspects of a person's personality and behavioral repertoire, family members may continue to see the injured person in the light of past experience until many many new and unexpected interactions slowly erode the old expectations and build new ones. When observing their injured person, it may take some family members months--even years--to

In short, when the TBI is relatively recent, family members may not yet be able to appreciate the seriousness of their loved one's behavioral disabilities. They are not denying the problems, they simply may not see them. Two years down the line, if serious problems are not yet acknowledged by a close family member, that is probably true denial. Families in the early stages following a TBI may benefit from help with mourning those qualities of the injured person that have been altered or lost and in establishing new and satisfying relationships with their injured member. It can be hoped that, as clinicians become more aware of the family aspect of the awareness problem, the difficulties faced by the close kin of a newly injured person will be appreciated and responded to appropriately.

Outcome evaluation

Outcome eval: early studies

Systematic outcome evaluations are a rather recent development. Early studies of outcome after TBI rehabilitation consistently reported improvement when comparing persons who had received rehabilitation with those who had not. However, the findings were often based on measurements of very different behavioral, cognitive, and real-life criteria of success. Further, persons gathering and preparing the data may have had a personal interest--as therapist or program manager, for example--that could bias their observations or interpretations of the data.

become objectively aware of the significant behavior changes--especially subtle differences in initiation and self-direction. Only then can family members learn how to deal effectively with the injured person, though maybe never comfortably.

The happy but often false expectation that the moderately to severely injured TBI patient will be essentially unchanged by the injury continues to be supported by the language clinicians use. When the surgeon comes out of the operating room to tell the anxious family that their son will "recover" from his cranial injury, he means that the wound will heal and the patient will probably walk and talk again. However, the word "recover" has a different meaning for the lay population. "Recover" implies a return to the preinjury state, like getting over a sore throat or a simple long bone fracture. And this is what the family hears and expects--until day to day confrontations with reality finally dissolves their hopes and most optimistic expectations.

A third source of happy and unrealistic expectations comes from the entertainment world. We've all seen movies in which an actor receiving an apparently resounding blow to the head may fall down but soon gets up to resume previous activity as if nothing bad had happened. Comic books and cartoon strips also take head injuries lightly. Among the worst offenders are the detective novels in which the detective hero is knocked unconscious, awakens the next morning in the apartment of the beautiful heroine who revivies him with orange juice and coffee--sometimes bacon and eggs. The next chapter finds him out and about, as clever and energetic--and headache free--as ever.

In one sample of five studies dating from 1984 to 1994, outcome measures included cognitive tests (WAIS and Wechsler Memory Scale-1), the Katz Adjustment Scale (1), the Employability Rating Scale (1), home-made questionnaires (3), Portland Adaptability Inventory--now M-PAI (1), and the Traumatic Coma Data Bank Questionnaire (1). They all used work and/or productive activity as the outcome criterion but their findings could not be compared since the different measures evaluated quite different aspects of behavior. Thus, in one study "productive activity" was correlated with cognitive impairment; in another study the scores on the Employability Rating Scale predicted "productive activity." Confounding these data for persons interested in TBI rehabilitation were two of the studies in which 52.2% and 31%, of subjects had CNS conditions other than TBI.

Also obscuring any possibility of drawing reliable conclusions from these early studies were the mismatches of the different groups being compared. Rarely were all of the important variables reported, such as age, education, cultural background, site and size of injured, and time since injury, which made comparisons between and even within studies virtually impossible.

Outcome eval: recent studies

In recent years this situation seems to have not greatly changed. A just-published in-depth study of outcome for multidisciplinary TBI rehabilitation programs found that out of 174 possible studies only 12 met appropriate research criteria for strength of evidence but four of these had a high risk of bias leaving just

eight that qualified for this study. Strength of evidence depends on such study characteristics as the statistical validation and appropriateness of the measures on which study findings are based, on the number of subjects in the study and how well-matched they are, and timing of outcome measurements. This most recent comparison of TBI rehabilitation outcome studies did not demonstrate any differences in the effectiveness of different treatments.

The bad news coming from this study is that having so few studies meeting satisfactory research criteria does not allow for substantial answers about the effectiveness of TBI rehabilitation programs and it limits comparisons within and between studies. The good news is that this study demonstrates progress in knowing what is needed for effective outcome evaluations, and it points to measures with which objective, quantifiable, and reliable data can be obtained.

A good outcome measure

The need to compare data across studies is now being addressed both by standardized scales and questionnaires for measuring outcome and by rehabilitation programs that use the same measures enabling them to share and compare meaningful data. The most comprehensive collection of evaluation procedures for measuring the many different facets of outcome is Robyn Tate's A compendium of tests, scales and questionnaires: The practitioner's guide to measuring outcomes after acquired brain impairment. The measures--all 140 of them--are organized according to the International Classification of Functioning.

Disability and Health (ICF). Thus the book's sections are : A. Body functions-- which includes measures of cognitive functions and emotional states; B. Activities and participation; C. Contextual factors--which concern supports or limitations of the environment in which the injured person lives; and D. Multi-domain scales. These latter scales are most relevant for measuring TBI outcome as they cover a range of abilities, behaviors, and situations which together can provide a sense of how well the person with a TBI might function in real life.

Many of these measures can be downloaded from COMBI: the Center for Outcome Measurement in Brain Injury.

M-PAI items

Among these you can find the Mayo-Portland Adaptability Inventory which, I am pleased to say, many of this country's major rehabilitation centers now use. I developed this measure as the PAI in the 1980s as part of a VA funded research project. when I needed to identify the behavioral obstacles due to brain injury which kept my study subjects from resuming an independent life once they were physically fit and cognitively competent. While at the Mayo Clinic, Jim Malec--now Professor in the School of Medicine of the University of Indiana and Research Director at the Rehabilitation Hospital of Indiana--undertook the heroic task of fine-scaling and standardizing the PAI which then became the M-PAI. Dr. Malec made it available to COMBI so that anyone who knows how to download pages from a computer can have a copy of the M-PAI. It is also available in most of the major European languages. A copyright permits free use of the M-PAI but forbids its sale.

Rehabilitation programs interested in contributing to a growing data pool for evaluating and comparing their work with others as well as providing standardized comparisons for individual patients' progress can send M-PAI answer sheets to Inventive Software Solutions which also does the scoring, ensuring accurate data at a reasonable rate.

Of course application of these measures need not be limited to outcome. Many measures presented in Dr. Tate's book or available through COMBI are also used to document spontaneous improvements in the early stages of a TBI and in persons with TBI who remain untreated. Many of them can be invaluable for following one or another aspect of progress during the course of rehabilitation. Further, data from broad-gauged measures such as the M-PAI can be used to help families better understand the assets and problems of their injured member. Scores on repeated measurements may also demonstrate improvements to the family when they may not be obvious on casual observation.

Preparing this review has been a happy undertaking as it has reminded me of the progress made in rehabilitation-relevant knowledge and treatment focus since the early 1920s when Kurt Goldstein became interested in the plight of head injured veterans of WWI.

Where we are now

My sense is that in a comprehensive history of TBI rehabilitation written two or three decades from now, we'll be seen as somewhere around the midpoint in the development of the field and of the research strategies and techniques so necessary

for genuine progress. Halfway means a lot of good has been accomplished. It also means that, for those of you working in TBI rehabilitation and your students, many interesting challenges lie ahead.