THE JOHN STANLEY COULTER MEMORIAL LECTURE

Pushing the Frames of Reference in Traumatic Brain Injury Rehabilitation

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Cognitive rehabilitation is an empirically based field driven by multiple sources of activities and knowledge bases. Drawing on frames of reference provided by rehabilitation, neuropsychology, and rehabilitation psychology, cognitive rehabilitation has evolved to a point where studies have been generated to qualify for consideration in tables of evidence. At the center of cognitive rehabilitation is the effort to teach people to overcome or adapt to limitations. While rehabilitation has traditionally been focused on activity, a recent trend in the literature is to incorporate the individual’s experience into a frame of reference for rehabilitation. Emphasizing the experience of the person in the situation fits into cognitive rehabilitation and raises the bar for rehabilitation not only in viewing rehabilitation as an activity to relieve burdens but also in terms of how rehabilitants come to grips with limitations. Dealing with limitations is an important indicator of mental health.

Key Words: Brain injuries; Neuropsychology; Rehabilitation.

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It is a privilege to be invited to deliver the 2004 Coulter Lecture. Although the honor of presenting this lecture is professional, I would be remiss not to mention the personal satisfaction to be nominated by colleagues with whom I have enjoyed working for many years. When I started out in rehabilitation more than half a century ago as a clinical psychologist in a rehabilitation setting, I was puzzled. Engaging a person with brain damage provoked 3 immediate questions. What does one diagnose, that is, beyond affirming the presence of brain damage, which was usually indicated in the referral? What does one treat? And what does one research? The questions were clearly interrelated. To probe further, I asked how does one know what to diagnose? What to research? Basically, I had an idea of the mechanics of my job but did not have a clear picture of how to go about dealing with the issues beyond the mechanics.

One had to rely on the literature and clinical anecdote to serve as reference points or paradigms for thinking and practice. These reference points were often dramatic if you had a teacher who was a good actor. Anecdotes had the virtue of stimulation and inspiration—not a bad thing, but they were largely based on faith. Casting about for reference points that existed at that time, 3 bodies of knowledge seemed to guide answers to my questions: medical rehabilitation, clinical neuropsychology, and rehabilitation psychology. They offered ideas and tools to approach the questions raised but posed an issue of how to mine them and balance them to answer my questions. These reference points admittedly were private and subjective and, of course, biased. They were imprecise and broad fields of study, and when one took a closer look, there was lack of a firm foundation of evidence in each of them. During the 20th century, all 3 moved toward such a foundation.

Like Rip Van Winkle, I can look back and ask what has happened to these reference points. But unlike Rip Van Winkle, having been immersed in these fields, it is harder to identify change if one is part of the process. Advances in all 3 reference points have been propelled by practice and research that has proliferated since World War II. To track their paths, given the sprawling nature of their content, is daunting. To project future paths is risky, for practice and research progress along several lines, in some cases by incremental increases through refinement of procedures, in others by developments from areas outside the field, by new demands on service delivery, or by fashion (eg, witness the fate of the Rorschach ink blot test, which is rarely used now in rehabilitation settings). It is difficult to set markers for development. The recent trend in using tables of evidence is a useful tool in establishing public credibility, although one could argue that these tables only serve as thresholds for practice and lack schemata for translating evidence into practice. However, tables of evidence may be used to track progress in our knowledge base. Changes have been striking. Guidelines for stroke rehabilitation1 that were developed in the early 1990s show 57 recommendations for practice, of which 79% are based on clinical judgment of a panel of experts. Only 21% are based on scientific evidence. Of these, only 4 were based on practice in actual rehabilitation programs—coordination of services, prevention of recurrent stroke, prevention of venous thrombosis, and diagnosis and treatment of depression. By 2003, the Study Group for Physiatric Education2 included a summary of the findings of the American Congress of Rehabilitation Medicine’s (ACRM) Brain Injury Interdisciplinary Special Interest Group (ISIG) task force.3 With meta-analyses and critical reviews, bodies of scientists are looking over the shoulders of other bodies of scientists to sift through and evaluate studies. In the last decade, 3 reviews on the efficacy of cognitive rehabilitation have come to somewhat different conclusions.3,4 The ACRM ISIG5 is the most detailed, permitting tracking of outcome studies over the past 3 decades. In considering studies that qualify as scientifically acceptable, there are more in the decade of the 1990s (N = 68) than in the 2 previous decades combined (N = 60). Clearly, the number and pace of outcome studies that qualify for consideration as evidence is increasing. In addition, certain areas (eg, memory, perception, aphasia) have many more studies than holistic and multidisciplinary studies. Many...
reasons could be offered for this, but in the end the reviewers recommended a comprehensive, holistic approach, for which there is only 1 class 1 study because it deals with the complex interactions of cognitive, functional, and social impairments with the goal of alleviating disability and handicapping conditions.

THE ORIGINAL VISION
Rehabilitation provides the context and the setting for seeing patients. It arose as part of a surge in efforts after World War II to alleviate problems caused by trauma or disease that left people to live with a disability after they were diagnosed and treated. Society was upbeat and expansive with a “can do” mind set. Rehabilitation offered practical solutions to residual functional limitations in the context of a team approach, calling on disciplines that had previously been considered outside the mainstream of medical care. The idea of 1-stop shopping for people with disabilities caught on and was exported all over the world. As part of the Cold War, in the 1970s Congress authorized the exportation of knowledge about disabilities and rehabilitation to the free world. Under pressure to cut budgets and show benefits for US citizens, Congress modified legislation to read “Conduct a program for international rehabilitation research . . . for the purpose of developing new knowledge and methods in the rehabilitation of handicapped individuals in the United States . . . initiating a program to exchange experts and technical assistance in the field of rehabilitation of handicapped individuals with other nations as a means of increasing the levels of skills of rehabilitation personnel.”10 The upbeat quality and optimism were personified by the wonderful and creative team assembled by Howard Rusk, from a variety of backgrounds and disciplines.7

Rehabilitation psychology crystallized as a field after a national conference sponsored by the American Psychological Association.11 The conference laid down a definition of rehabilitation psychology as a basis for professional activities. Because many of the pioneers were not trained as clinicians, they framed their inquiry into social psychologic dimensions in terms of the situation of the person with a disability. I visited Tamara Dembo, a psychologist who was teaching in New York City. I asked her about applying the level of aspiration methods that she had pioneered to study goal setting in rehabilitation. She suggested that to be effective one had to take into account the perspective of the insider in a rehabilitation setting as a path for useful knowledge and posed a number of questions that flow from this stance. First, what occurs in asking for help and rendering help? This breaks down into issues of dependency and trust. Both of these occur in a situation with an imbalance of power between an expert who offers help and a patient who receives help. Second, what is the loss experience associated with disability? How is the experience of loss related to a value system? What determines the value of what is lost and why can some people accept loss, while others cannot? Kahneman,7 in his Nobel prize lecture, noted that a person who has $4,000,000 and loses $200,000 may be depressed, whereas a person with $1,000,000 who earns $50,000 may be happy. Values are clearly determined by a frame of reference. And third, people with disabilities are a neglected, minority group, unwittingly disenfranchised by society. These kinds of questions—social, political, and clinical—were posed before check lists and rating scales became enabling tools to yield data to help illuminate answers.

Clinical neuropsychology was an emerging field, focusing on explicating brain behavior relationships by adapting conventional clinical tests to neurologic populations and by applying methods from cognitive and experimental psychol-
alization. Along with industrialization came: (1) standards as to what services or programs could be called rehabilitation. Standards prodded by consumer advocates took hold via the Commission on the Accreditation of Rehabilitation Facilities, which in the 1960s started to examine the many programs with questionable practices that arose to take advantage of liberal veterans’ benefit programs. (2) A vocabulary of functional limitations to help define the goals and outcomes of its activities. (3) Workers who served to professionalize the field while maintaining their identity in the separate professions in which they have been trained. ACRM is an example of this—it developed specialty and special interest groups within the specialties. (4) The success of rehabilitation brought a demand for continuity of care first from inpatient to outpatient settings, from outpatient hospital settings to subacute settings in nursing homes, to vocational and community settings, and to home delivery of services. (5) Hospital systems and granting agencies grouped interests around specific impairment groups as product lines, for example, stroke, multiple sclerosis, and traumatic brain injury (TBI), in accord with larger trends. (6) It adopted business models with emphasis on cost savings and efficiency to go along with effectiveness. Like the rest of the health care system, patients have become consumers and practitioners have become providers. Parenthetically, department stores now refer to customers as guests and some VIP sections of hospitals are doing the same.

The playing field of rehabilitation is continually changing. Demands arising from these changes are shaped in part by research, but they also shape research. For example, studies conducted over 30 years ago on the treatment of visual neglect in stroke patients with right-hemisphere damage participating in inpatient rehabilitation programs could not be conducted today. At that time, stroke patients typically had stays of 30 to 40 days, while now their stays typically last less than 10 days. Operational research to answer questions about intensity of treatment for different patients is now possible because of the large databases that have been assembled.

**Developments in Neuropsychology**

There have been many approaches and descriptions of mental life. Clinical neuropsychologists have acted as neuropsychopathologists, emphasizing cognitive components of mental life and behavior. The major developments of relevance to rehabilitation have been: (1) refinements and extensions of test procedures to provide sounder psychometric properties and population specificity; (2) articulating the domains of cognitive dysfunction, particularly with regard to executive functions and working memory; (3) predicting and assessing indicators of recovery and treatment; and (4) investigating relationships between brain and behavior. Blending neuropsychology with rehabilitation has led to a useful accumulation of knowledge and has expanded beyond cognitive disturbance to include emotional disturbances after acquired brain injury and stroke.

Of course in rehabilitation, our interests went beyond diagnosis. Our work started with providing procedures to address impairments, rather than bypassing them, by altering task conditions to permit people to develop compensatory strategies to perform a task successfully. In the case of visuospatial neglect, we found that we could ameliorate profound impairments by developing a cuing system designed to grasp the patient’s attention and to maintain it. The formal benefits and limitations of this approach have been evaluated and reviewed in several places. This approach emphasized addressing the attention component of visual perception and seemed to work well for problems in 2-dimensional space but did not generalize well into 3-dimensional activities, which are major features of activities of daily living. I would offer 2 observations. First, other approaches to treat neglect have burgeoned and a line of approach developed by Robertson and his colleagues has been pursued in a series of single-case studies. This approach features activation of the impaired limb. Second, there are additional lessons to learn: a treater learns more about obstacles to successful performance from a perspective of trying to correct a problem than from a test sample. In attempting to teach compensatory strategies to cognitively impaired people, it is clear that cognitive deficits are seldom isolated—they coexist with other deficits. Neuropsychologists are only now beginning to explore the layering of cognitive deficits.

**Back to the Person in the Situation**

The earlier work of the rehabilitation psychologists concerned with physical disability had been largely at the periphery of rehabilitation research and service delivery with TBI populations. Research had focused on identifying more precisely who was being served, what the treatment was, and what the outcomes of treatment were. The phenomenology of the person was slowly brought back into the clinical picture by the nature of the complaints and manifestations of the sequelae of TBI in outpatient populations in which the traditional emphasis on motor and speech problems shifted to a concern with emotional and neurobehavioral issues. Attempts were made to translate many of these issues into psychiatric categories and there is a growing body of data on the incidence of emotional disturbances.

Concern with affective issues forces the deliverers of services to reexamine the position of the person and his/her experience. This theme has been picked up in a number of recent paths of research.

**Accepting help.** Earlier rehabilitation psychologists discussed denial of disability in terms of failure to incorporate change into one’s life situation. Therapy was viewed as an educational effort to explore the person’s value system and to reeducate the person by providing a boundary or frame of reference for the loss. Denial in the context of acquired brain injury has these elements but also has more focus on the individual’s inability to identify and engage in problem solving both on a neurologic and psychologic basis. I would argue that, in a sense, the person with denial has a bias or prejudice against receiving information and has a deaf ear for feedback. From a social psychologic perspective, Aaronson has shown how bias expressed in racial prejudice in school children can be overcome by engagement of biracial pairs of children in solving a problem in which success was dependent on cooperation. Dealing with denial may take different paths for different syndromes. For example, in trying to make a student out of a stroke patient, the major way of overcoming denial is to focus on a perceptual problem that could be made apparent and meaningful and, at the same time, provide a solution. Thus, a patient with right-brain damage and neglect might be shown a sample of his/her own handwriting or a difficulty in reading a newspaper and then provided with a cue to alter looking habits to overcome the problem. The treater can succeed when the patient is able to appreciate a difficulty in an important task and the difficulty is immediately followed by cues for a practical solution. This requires a proactive role for the treater, in which the treater knows a patient well enough to judge the relevance of the task, the timing for introducing the problem, and the appropriate feedback. By contrast, in holistic TBI programs, unawareness issues are more related to planning and executive dysfunctioning.
group setting creates a situation in which patients can be less defensive about their weaknesses and be more open to the comment of outsiders. Use of groups to enhance utilization of software for cognitive training has been successfully adapted for schizophrenia.

Quality of life. Rusk formulated a guiding principle for rehabilitation based on Osler’s phrase “activity alleviates anxiety.” Measurement and treatment in rehabilitation have followed this philosophy. Rehabilitationists have been concerned with the idea of quality of life (QOL) but have lagged in incorporating it into formalized terms because of the difficulty in defining QOL in precise operational terms and the hesitancy of third-party payers to support the idea on a number of grounds, including problems of measurement. Although public health indicators may rely on objective markers (eg, income, education level), for most people there is an experiential, evaluative component to the definition. Johnston and Miklos have proposed that QOL includes activities and experiences or subjective components of experience and have reviewed different approaches to their measurement. Perhaps Rusk’s motto can be altered to read, “The experience of activity alleviates anxiety.” There have been different approaches to assessment of subjective components, but there is agreement that QOL includes an evaluation of the fit between past expectancy and achievement. Clinical practice recognizes the importance of subjective experience when formalized choices are presented to patients.

Subjective components of treatment. Cicerone et al used assessment of subjective experience in a direct way. In assessing the outcomes of an intervention study that compared an intensive and a conventional postacute treatment program for TBI, Cicerone found that both groups improved on the Community Integration Questionnaire (CIQ). Satisfaction with community integration was not related to actual CIQ outcomes. However, satisfaction with cognitive function made a significant contribution to posttreatment community integration. The presumption is that satisfaction with cognitive function is related to self-efficacy and is an indicator of distress. To be effective, rehabilitation after TBI must address patients’ attitudes and beliefs in addition to their cognitive abilities; remediation of cognitive abilities may have more generalized effects if it increases self-efficacy beliefs as well as trains cognitive skills.

Rath et al found that people with mild to moderate TBI had slower reactions than a normative sample. In a study to improve problem solving in TBI, Rath found that the slowest subjects showed the most improvement after treatment for problem solving. Rath argues that in problem-solving situations, a difficulty arises not only in logical thinking but also in a disturbance in affective regulation so that people become too emotionally upset to think. The treatment reduces the emotional upset. People who are slow benefit from the treatment because the delay in processing causes a sense of panic—it is difficult to keep track of the information. The treatment is designed to teach emotional self-regulation, which helps reduce distress and permits more effective ways of dealing with information before engaging in logical thinking.

Power relationships. Although patient and provider relationships have generally been viewed from a psychotherapeutic perspective of transference, ways of reducing imbalance of power were discussed by the early rehabilitation psychologists. One way of reducing the feeling of power imbalance is openness. Thus, there is 1 feature of holistic programs that has not been well described. Within the context of highly structured programs with well-defined roles, all participants, including patients and staff, meet in a group, introduce the members, and state why they are there. The approach encourages all participants to move a step closer to the insider’s perspective, thereby reducing the perceived power imbalance. In a recent study, subjects with acquired brain injury living in the community were invited to design their own group program by selecting topics suitable from their daily life activities and by selecting the order of workshops. Brown and Gordon have called attention to another aspect of the situation of the insider, namely, the imbalance in the power relationships between the provider and the recipient of services in program evaluation. They outline a methodology for patient participation in program evaluation.

RAISING THE BAR FOR COGNITIVE REHABILITATION

Although the bulk of rehabilitation efforts are designed to reduce dependency, a further goal is to restore health, by accepting limitations on a voluntary basis. This is manifested by a cessation of mourning, a capacity for enjoyment, and restoration of self-esteem.

Ben-Yishay and Daniels-Zide have noted that Kurt Goldstein, a pioneer in TBI rehabilitation during World War I, argued that 1 function of rehabilitation is to minimize the catastrophic response and severe anxiety experienced by people with TBI by providing a safe, secure, and structured environment. But Goldstein went beyond this. He was concerned with the notion of the healthy organism and restoration to health. One component of health, according to Goldstein, is being able to accept necessary restrictions on a voluntary basis. The acceptance is not so much an act of submission to difficult reality, as much as it is an act of maintaining engagement while recognizing that, despite limitations, one continues to search for optimal solutions to problems. Holistic rehabilitation while attempting to reduce dependency and functional limitations and to enhance productivity and role engagement, also attempts to achieve acceptance. As a first step toward an empirical definition of acceptance, Ben-Yishay and Daniels-Zide included cessation of mourning, morale, satisfaction with rehabilitation outcomes, capacity for enjoyment, and restored self-esteem. Subjects, who showed acceptance on follow-up, described placing more effort into their rehabilitation, found life to be more meaningful, were more productive vocationally, had a broader social life, were able to maintain intimate relationships, and were more at peace with themselves. The findings suggest that 1 desirable outcome of rehabilitation is acceptance.

Acceptance and/or denial of limitations is emerging as a criterion in arriving at an empirical definition of mental health. Several groups have noted that a realistic acceptance of the destiny imposed by one’s time and place in the world is a marker of mental health. The concept of health is much more elusive than the concept of illness. For example, health is more than the absence of symptoms. For internists, the antonym of illness is fitness. Similarly, mental health is more than the absence of symptoms. Spurred in part by a Presidential commission for a mandate for prevention of mental illness, there have recently been models aiming to formulate definitions of mental health with sufficient rigor to permit empirical investigation. Although the models differ, there is considerable overlap among them and with current research with TBI populations. Vaillant cites 6 groups that have been pursuing models that lend themselves to empirical definitions of mental health, including the group that developed the Global Assessment of Functioning Scale, of the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, as a global measure and the
groups moving toward a definition of psychologic well-being. The notion of acceptance as an outcome measure immediately raises a red flag for researchers. From a policy standpoint, it is hard enough to persuade third parties to pay for illness and restoration of function. The notion of paying for health is a far reach given today’s economic climate. However, prevention of illness and disability is not an outrageous consideration. If people who accept limitations show reduced health costs and increased productivity, then acceptance is a meaningful goal.

CONCLUSIONS

Like politics, all research is local, but the results have larger consequences. Unlike politics, results are cumulative. I must confess that when I started I had hoped to learn more about how people with brain injury learn and how they are taught and to emerge with some grand theory of learning. Instead, I found that cognitive rehabilitation, drawing on the initial foundations of rehabilitation, neuropsychology, and rehabilitation psychology, has advanced enormously. The challenge has always been in trying to translate experience into research. This challenge is ongoing. The experience and the research have developed a field where reference points for clinical decisions are bolstered by more refined and user-friendly tools and relevant ideas.

References


