An Approach to Cognitive Rehabilitation in Multiple Sclerosis

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A cognitive rehabilitation approach is described for individuals with Multiple Sclerosis (MS) who are experiencing cognitive difficulties. The position taken is that compensatory strategies which focus on structuring, scheduling, and recording can have a significant positive impact on an individual's functioning. By avoiding reliance on impaired cognitive functions, the stresses of daily living can be minimized, performance abilities can be maximized, and general activity level can be increased. The current approach is distinguished from more traditional approaches to cognitive rehabilitation and guidelines for the application of cognitive rehabilitation strategies are described. The advantages and the limitations of the current approach are discussed.

It is becoming increasingly clear that a substantial proportion of individuals with Multiple Sclerosis (MS) will experience cognitive deficits (Rao, 1986). Recent research indicates that measurable cognitive deterioration may be evident in more than half of individuals diagnosed with relapsing-remitting MS, and an even higher percentage of individuals diagnosed with chronic-progressive MS (Heaton, Nelson, Thompson, Burks, & Franklin, 1985). While it remains unclear whether cognitive deterioration increases with duration of illness, there is evidence to suggest that deterioration may be apparent within the first year of diagnosis (Lyon-Caen, Jouvent, Hauser, Chaunu, Benoit, Widlocher, & Lhermitte, 1986; Rao, Hammeke, McQuillen, Khatri, & Lloyd, 1984).

Research to date has focussed primarily on describing the pattern of cognitive deficits which results from the brain dysfunction caused by MS. There have been few attempts to describe how these deficits impact on the individual's daily life activities. Even less attention has been given to developing viable means of managing the cognitive deficits associated with MS.

The purpose of this paper is to describe a rehabilitation approach to the cognitive problems experienced by individuals with MS. The approach described in this paper has evolved from our experience in the rehabilitation of individuals with MS. The current approach will be distinguished from more traditional approaches to cognitive rehabilitation and guidelines for the application of cognitive rehabilitation strategies will be described. Efforts will be made to highlight both the advantages as well as the limitations of the current approach.

COGNITIVE DEFICITS IN MULTIPLE SCLEROSIS

There have been several attempts to specify the nature of the cognitive deficits that are likely to result from MS. While this literature has been criticized on methodological and conceptual grounds, sufficient consistencies have been observed to allow for a general description of probable areas of dysfunction (Rao, 1986). Several investigators have reported that individuals with MS perform poorly on measures of attention and concentration, and may experience a slowing of mental processes (Ivnik, Matthews, Cleeeland, & Hopper, 1970; Reitan, Reed, & Dyken, 1971; Rao, Aubin-Faubert, & Leo, 1989). Research also shows that individuals with MS are impaired in their ability to learn and recall new information (Caine, Bamford, Schiffen, Shoulson, & Levy, 1986; Heaton et al., 1986; Lyon-Caen et al., 1986).
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There are also indications that MS may interfere with conceptual and abstract reasoning (Heaton et al., 1986; Lorenzo, 1986; Peyser, Edwards, Posner, & Folskov, 1980; Rao et al., 1984). While deficits in visual-spatial processing have been frequently reported, it is unclear whether these are the result of cognitive problems or whether they can be attributed to sensory and motor problems (Rao. 1986). There are still insufficient data available to make statements about the rate and progression of cognitive deterioration in MS.

Several investigators have examined cognitive function in MS by comparing the test results of individuals with MS to data from normative samples (Heaton et al., 1985; Lyon-Caen at al., 1986). This methodology is problematic since comparisons to normative samples do not take into account individuals' premorbid level of cognitive functioning nor do they provide an index of the impact of cognitive deterioration on the individual's daily functioning. The disabling nature of cognitive deterioration will be determined to a large extent by the cognitive demands of the individual's environment. For example, individuals with premorbidly high intellectual functioning are likely to live within cognitive demanding environments. These individuals are likely to be employed in areas which place a premium on cognitive function, and they are likely to have social relations with other highly functioning individuals. To date, the ecological context in which cognitive deterioration occurs has been largely ignored.

While neuropsychological findings reveal a variety of cognitive deficits associated with MS, affected individuals most frequently report memory difficulties. Individuals with MS who are referred for cognitive rehabilitation report memory problems such as forgetting the content of conversations, they may forget others' names, or they may forget to attend meetings or appointments. These individuals also report that they have difficulty engaging in tasks requiring sustained attention or concentration such as watching television, reading a book, or engaging in social interaction. The disruptions in functioning resulting from attentional and memory problems tend to impact negatively on the individual's activity patterns over time. Activities which place demands on impaired cognitive abilities are likely to be experienced as increasingly difficult, ultimately leading to a reduction in activity level. The emotional distress consequent to disruptions in social functioning may also lead to withdrawal from social activities. Individuals with MS frequently report decreased interest in activities which have become difficult.

Reduced activity in MS may also be the result of deficits in the area of planning and organization. This area of functioning has received less attention in the neuropsychological literature on MS given that it is assessed primarily through tests of visual-spatial processing. As noted earlier, the results of visual-spatial measures of cognitive function are often confounded by sensory and motor deficits. However, most activities of daily living require some degree of planning and organization. As such, deficits in this area are likely to be disruptive to daily functioning. Individuals with MS may report difficulties in organizing or initiating activities, planning a course of action, or making decisions. The reductions in activity which result from deficits in planning and organization may be mistakenly interpreted by others as indicative of a lack of motivation. This interpretation is reinforced by the fluctuating nature of cognitive dysfunction, where individuals may experience considerable difficulty performing a task which may have appeared effortless a few days earlier. Attributing the problems of cognitive dysfunction to lack of motivation can give rise to considerable interpersonal conflict.

The adverse impact of cognitive deterioration on daily functioning must also be considered in relation to the individuals' physical status. MS is associated with a variety of sensory and motor dysfunctions. Sensory deficits include visual difficulties, altered sensation such as tingling or numbness. Motor difficulties may include limb weakness, spasticity, tremor, decreased coordination and fatigue. These deficits frequently interfere with ambulation as well as with many activities requiring coordinated muscle movement (Harper, Harper, Chambers, Cino, & Singer, 1986).
While the exact nature and rate of physical deterioration is difficult to predict, the natural course of the disease is reflected in the progressively decreased capacity for physical activity (Weinshenker & Ebers, 1987). Given that most activities in daily living require both physical and cognitive functions, the individual with MS may become disabled as a result of a deterioration in physical functioning, deterioration in cognitive functioning, or both. Cognitive rehabilitation approaches to MS need to consider that an individual’s ability to engage in a particular activity may change abruptly as a result of exacerbations of physical symptoms.

**APPROACHES TO COGNITIVE REHABILITATION**

Approaches to cognitive rehabilitation can be conceptualized broadly either as restorative or compensatory (Sohlberg & Mateer, 1987). Restorative approaches focus on identifying specific deficits areas, and providing remedial training of identified deficits (Diller, 1976; Lewinsohn, Daniker, & Kikel, 1977; Sohlberg & Mateer, 1989). Target areas are selected and behavioral interventions are aimed at increasing an individual’s performance proficiency in the deficit areas (Serin, Delocke, Moulard, & Rouselle, 1980; Lynch, 1983). Through training and increased stimulation, the aim of these training programs is to promote recovery of function. The efficacy of these training approaches is assessed through changes in performance on tests of cognitive function.

Restorative approaches to cognitive rehabilitation have been used primarily with closed head injury and stroke. Overall, outcome evaluations have yielded disappointing results. While therapeutic gains have been demonstrated, they have rarely been shown to generalize beyond the training setting (Godfrey & Knight, 1985; Schacter, Rich, & Stampp, 1985).

Compensatory approaches to cognitive rehabilitation differ from restorative approaches in that they do not attempt to promote recovery of function. Rather, compensatory approaches focus on maximizing an individual’s functional abilities within a naturalistic environment. Training may include learning the use of memory aids such as record keeping or mnemonics, or more general organizational strategies. Interventions may also be aimed at modifying environments to minimize the extent to which they place demands on areas of impaired function.

Compensatory approaches to cognitive rehabilitation have been criticized for targeting specific functions which may not be generalizable, for focusing on the symptoms rather than the cause of cognitive dysfunction and for placing heavy demands on cognitive resources which may be impaired (Sohlberg & Mateer, 1989). While these may be valid criticisms of compensatory strategies in the rehabilitation of head injured, they may be less problematic when applied to individuals with MS suffering from cognitive deficits.

The position taken here is that compensatory approaches may be the most suitable cognitive rehabilitative approach for individuals with MS. Restorative approaches have been advocated in the rehabilitation of traumatic head injury (Diller, 1976; Sohlberg & Mateer, 1989). However, the cognitive dysfunction associated with MS differs in several ways from the cognitive dysfunction associated with more traumatic causes of brain injury. First, cognitive dysfunction in MS is insidious in onset thus initially disrupting only the most demanding or high level tasks in the individual’s environment. In addition, the cognitive problems associated with MS are not expected to follow a natural course of recovery as is the case with head injury or stroke. Rather, MS is more likely to result in a progressive deterioration of function. Intensive cognitive retraining programs may not be cost effective if therapeutic gains are lost when the individual experiences a subsequent exacerbation resulting in increased physical or cognitive impairment.

**COGNITIVE REHABILITATION IN MULTIPLE SCLEROSIS**

A viable approach to cognitive rehabilitation in MS will need to satisfy several criteria: it should involve a minimum amount of intervention, it
should focus on high level cognitive functions, and it should be applicable to a variety of environmental settings. The current approach adopts a philosophy similar to that advocated in physical rehabilitation. Specifically, the overall goal of intervention is to maximize the individual's functioning in spite of his or her deficits (Delisa, Ham mond, Mikulic, & Miller, 1985; Levine, 1985). The focus of intervention is on developing compensatory strategies to circumvent the limitations or constraints that result from cognitive deficits. No attempt is made to provide remedial training in deficit areas.

The proposed intervention program focuses on three main areas: structuring, scheduling, and recording. Attempts are made to increase the structure and consistency in the individual's environment. The rationale is that environments which have a stable structure place fewer demands on cognitive functions such as planning and organization, and memory. Increased environmental structure also tends to be associated with a certain degree of predictability which can be comforting to an individual experiencing cognitive deterioration. A major component of the current approach is that individuals are required to schedule their daily activities in a day calendar. Scheduling increases structure and facilitates planning. In order to manage memory problems, individuals are instructed to record the details of daily events in their day calendar.

A major strength of this approach is that it capitalizes on individuals' natural tendency to engage in compensatory strategies in the face of deteriorating function (Baltes & Lindenberger, 1988; Salthouse, 1984). The following sections outline different compensatory strategies which can be applied in the cognitive rehabilitation of individuals with MS. Problem areas are likely to differ across individuals and thus, rehabilitative approaches must remain sufficiently flexible. The procedures outlined in this paper are based on the work of several cognitive rehabilitation specialists, and have been combined into a comprehensive program that is tailored to the needs of the MS population.

**Assessment**

A cognitive rehabilitation program begins with a comprehensive neuropsychological evaluation including tests of intellectual function, memory function, abstract and conceptual reasoning, and emotional status. The assessment information is important in determining the individuals' cognitive strengths and weaknesses, as well as providing an index of premorbid level of cognitive functioning. The Information and Vocabulary subtests of the WAIS-R are considered to be adequate indices of premorbid functioning particularly if they are congruent with other indices of premorbid function such as educational level and occupation (Meador & Nichols, 1987; Russell, 1979).

Assessment must also consider the individual's environment because disability can only be defined within a particular context. The aim is to obtain information relevant to the cognitive demands of the individual's environment. For example, individuals who are employed are faced with different cognitive demands than individuals who are unemployed. Similarly, individuals employed in managerial positions are faced with different cognitive demands than individuals employed in unskilled occupations. Occupational Therapy assessments can provide important information concerning the demands of an individual's environment.

Efforts are made to determine the areas of daily functioning most affected by cognitive deficits. Individuals are questioned about the types of daily functions in which they experience most difficulty. Interventions are then designed to target problems within specific environmental contexts. If an individual is experiencing difficulty remembering appointment times at work, strategies may be developed to facilitate this process within the work setting rather than focusing on general memory functioning. Within this approach, disability is assessed as the interaction between an area of deficit and an environmental demand.

Prior to implementing intervention strategies, the results of the assessment are discussed with the client. The client's participation in specifying
targets of intervention is an integral component of treatment planning and likely contributes to treatment outcome. Family members are frequently involved in treatment planning and implementation. The cooperation of family members is required particularly when treatment involves changes to daily household routines.

**Memory**

Impaired memory function can have considerable negative impact in several areas of daily living. Memory deficits can lead to decreased performance in the work setting (e.g., forgetting the details of meetings), and to embarrassing situations in social contexts (e.g., forgetting others’ names). The debilitating effects of memory impairment can be reduced substantially with the use of an external memory aid such as a day calendar.

A day calendar can be useful in compensating for difficulties in the recall of information about past events (e.g., the details of a conversation), as well as the recall of future oriented information (e.g., appointment times). The type of day calendar which appears best suited for this task is one which represents the day of the week on the right side page, allowing space for hourly entries, and where the left side page is a lined blank page. Appointment times and activities can be scheduled on the right side page, and details of these activities can be recorded on the left side page.

As noted elsewhere (Mateer & Schiberg, 1989), the effective use of a day calendar requires some degree of training. Simply suggesting to clients that they purchase a day calendar is not likely to be effective. The client will require instruction and guidance concerning the type and amount of information to record, as well as when information should be recorded.

The utility of using a memory aid will be maximized if it can be targeted at a specific domain of functioning. It is also important to note that the most obtrusive and time consuming recording becomes, the more likely it is to be discontinued: It has been our experience that the more specific and time efficient the recording process, the more likely it is to be incorporated as a routine part of the client’s activities.

Individuals who are employed in office-based work may be trained in recording and summarizing the contents of meetings. This may take the form of a two stage process where information communicated in a meeting is first recorded on a notepad, and a summary of this information is later transcribed to a day calendar. Over time the day calendar becomes a useful record of information exchanged at meetings.

In the home environment, the day calendar can be useful for recording information which was communicated by telephone. It can also be useful for remembering to complete certain tasks or activities. Some clients may be instructed to purchase a watch which produces audible hourly signals in order to prompt them to check or record information in their day calendar (Gouvier, 1982). In the home setting, the day calendar becomes a record of daily activities and occurrences.

At the onset, the client’s record keeping should be monitored closely. If the day calendar contains information which is too detailed then it will not be an efficient memory device. Conversely, if it contains insufficient information, it will not be a useful memory device. The use of mnemonic strategies is not advocated since it places heavy demands on cognitive functions which may be impaired.

**Planning and Organization**

Problems related to deficits in planning and organization are more likely to be evident in the home as opposed to the work environment. Work environments typically dictate when certain activities begin, what tasks need to be completed, and when activities cease. Work environments also contain several routine activities. This degree of structure and consistency in the work environment reduces the degree to which individuals need to actively engage in planning and organization. When individuals, who are accustomed to working, find themselves at home, they frequently go through a period of general disorganization, reduced activity, and at times, depression. Along with the loss
of employment comes a loss of a substantial degree of structure and consistency in daily living.

The problems of disorganization and reduced activity can be managed by attempting to increase the degree of structure and consistency in the home environment. Clients may be instructed to schedule activities in their day calendar, and to attempt to incorporate these in a routine manner. Like the work environment, the home environment requires that several activities be carried out on a regular basis. Placing these activities within a consistent time schedule can increase the degree of structure in daily living. Given that the task of planning activities can be cognitively demanding, clients are instructed to plan their weekly activities at a time when they feel most alert. They are also encouraged to seek assistance from their spouse if they encounter difficulties.

Structure can also be increased by manipulating environmental characteristics. Unstructured environments can place heavy demands on cognitive function. An effective means of increasing the structure of an environment is to ensure that household items are always kept in the same place. Many individuals spontaneously attempt to incorporate such structure in their environment in response to failing cognitive function. Strategies may include keeping keys on a key rack, placing letters on the same shelf, or placing all phone messages on the same board. The cooperation of family members is important when attempting to increase and maintain structure in the home environment.

Safety Hazards

Work and home environments contain a variety of potentially hazardous activities. These may include the operation of electrical tools and appliances, or the operation of motor vehicles. As cognitive function deteriorates, individuals' ability to safely engage in these activities may be compromised.

Safety issues are frequently raised in the rehabilitation of individuals who have sustained head injury or stroke. Decisions are made concerning the individual's ability to return to an environment which may contain potential hazards. The situation differs for individuals with more progressive cognitive deterioration in that they are already living in an environment where the demands of safe functioning may begin to exceed their abilities. It is difficult to objectively evaluate the degree of risk associated with the performance of different activities. The safety hazards associated with deteriorating cognitive function will be determined to a large extent by the number and the nature of potentially hazardous activities in a particular environment. Clearly, the hazards associated with cognitive deterioration would be greater for an individual employed as an electrician, or driver, as opposed to an individual employed in a clerical position.

Clients can be provided with strategies to maximize the probability of safe functioning in their environments. For individuals in home environments, strategies may include remaining in the kitchen while cooking, purchasing appliances which turn off automatically when their function has been completed, using clock timers, or requesting the assistance of others. A clients' degree of mental alertness will also tend to vary through the day. Thus, they may be instructed to engage in potentially hazardous activities only when feeling rested and alert, or only under supervision. Suggestion may be made that driving be avoided when feeling fatigued or distractible. When assessment reveals severe deficits, suggestion may be made that certain activities be avoided completely.

Limitations

Most of our experience with cognitive rehabilitation in MS has been with individuals who are beginning to experience difficulties in the work setting. The aim has been to maximize the probability that the individual will be able to continue to meet the cognitive demands of the work environment. For individuals within the home environment, the aim has been primarily to increase activity and maximize safety.

It is apparent that the approach outlined in this paper requires a certain degree of cognitive
functioning. The application of compensatory approaches implies the ability to be aware of deficit areas as well as the ability to exercise control over these areas. Awareness, motivation, performance orientation, and high premorbid level of functioning have generally been associated with positive outcome.

A number of patient characteristics have been associated with poor outcome. In general, the more severe the cognitive deterioration, the lower the probability of positive outcome. Individuals with marked deficits in planning and organization do not appear to show significant improvement. These individuals often report a paucity of thought and an inability to initiate activity. Goal planning and execution are disrupted resulting in inactivity. In the absence of goal oriented behavior, compensatory approaches are not likely to be effective.

A small number of individuals with MS display euphoric-like reactions and a personality style characterized by impulsivity and poor judgment (Surridge, 1969). These characteristics have been associated with poor outcome. These individuals appear to lack the degree of awareness and the degree of behavioral control necessary to benefit from compensatory approaches to rehabilitation.

At times, clients who present with cognitive difficulties, also present with some degree of depression (Lyon-Caen et al., 1986). In severe cases, depression can interfere with progress in cognitive rehabilitation. In addition, depression may also be associated with impaired cognitive functioning. When levels of depression are moderate to severe, they should be treated prior to the start of cognitive rehabilitation. The symptoms of mild depression appear to remit with improvement in cognitive rehabilitation, and thus, may not require additional treatment.

Deficits in physical functioning may also interfere with clients' ability to take part in the cognitive rehabilitation program outlined here. Individuals with marked tremor or spasticity of the upper extremities have difficulty recording information in a day calendar. Similarly the use of a day calendar also requires adequate visual function which may be impaired in some individuals. The use of a dictaphone may be a more suitable recording device for individuals with motor or sensory deficits.

As with other areas of rehabilitation in MS, issues of treatment evaluation are problematic. Due to the unpredictable course of MS, spontaneous remissions or exacerbations can lead either to overestimates or underestimates of treatment efficacy. In addition, the goals of rehabilitation programs are frequently stated in terms of maximizing function given certain deficits, reducing rate of deterioration, or reducing the impact of deterioration. Within these general goals, treatment may be considered successful even in the absence of observable improvement. Problems such as these have plagued efforts to examine treatment outcome in rehabilitation.

In the area of compensatory cognitive rehabilitation, treatment success can only be assessed with respect to treatment goals. Given that the targets of intervention are defined in terms of deficits within a particular environmental context, treatment goals tend to vary considerably across individuals. In light of these considerations, the most heuristic approach to treatment evaluation may be idiothetic (e.g., multiple cases studies) with an emphasis on the identification of client or environment characteristics which are associated with treatment success or treatment failure.

SUMMARY

A cognitive rehabilitation approach was described for individuals with MS who are experiencing cognitive difficulties. The position taken here is that compensatory strategies which focus on structuring, scheduling and recording can have significant positive impact on an individual's functioning. By avoiding reliance on impaired cognitive functions, the stresses of daily living can be minimized, performance abilities can be maximized, and general activity level can be increased. Increased productivity and activity may also be reflected in more positive self-perceptions and more positive mood.

At the present time, the majority of individuals
with MS become disabled primarily as a function of physical rather than cognitive deficits. However, current advances in physical therapies, new development in assistive devices, and more accessible work environments are likely to increase the number of individuals with MS who remain actively involved in the work or home settings. As the number of physical obstacles to daily functioning are reduced, the debilitating effects of cognitive dysfunction will likely become more salient. Consequently, there will be an increased need for cognitive rehabilitation programs aimed at minimizing the negative impact of cognitive dysfunction.

In recent years there has been increased recognition that degree of disability is determined by a combination of several factors including physical, emotional, and social functioning. For individuals with MS, the situation is further complicated by the possibility of cognitive deterioration. As part of a growing awareness that effective rehabilitation requires multidisciplinary approaches targeting several deficit areas, cognitive rehabilitation programs are likely to become an integral component of MS rehabilitation.

Une approche cognitive de la réadaptation est décrite pour les personnes atteintes de sclérose en plaques (SEP-MS) qui éprouvent des problèmes cognitifs. Le point de vue adopté est que les stratégies compensatoires qui s'attachent à la structuration, à l'organisation et à l'enregistrement des expériences a un impact positif sur le fonctionnement de la personne. Si l'on évite de dépendre des fonctions cognitives défectueuses, il est possible de minimiser le stress de la vie quotidienne, de maximiser les capacités de fonctionnement et d'augmenter le niveau d'activité général. La présente approche se distingue des perspectives plus conventionnelles et l'application des stratégies de réadaptation cognitive est décrite. Les avantages et les limites de cette approche sont examinés.

REFERENCES


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