The Status of Brain Injury Rehabilitation

This is the first special issue of AJOT on rehabilitation after acquired brain injury. This somewhat surprising fact may be partly due to the relative youth of brain injury rehabilitation as a specialty. In 1980 there were fewer than 12 centers in the United States that specialized in brain injury rehabilitation, but this field has grown rapidly over the last 20 years with, more recently, some reduction in services. This paper attempts to account for some of these changes and describes factors that have led to the increased scrutiny of brain injury rehabilitation in the managed care environment.

An overview of the recent history of brain injury rehabilitation is provided, and areas of particular interest to occupational therapists are emphasized. By focusing on what we have learned about persons with brain injury, we will be in a better position to advocate for the provision of adequate and cost-effective services.

Every history, but particularly one written by a participant, is partial and necessarily incomplete. This historical overview provides one view as to how we have reached our current position. In this paper and throughout this special issue, the term brain injury predominantly refers to traumatic brain injury (TBI). TBI includes open and closed and focal and diffuse types of injuries. The prototypical TBI patient is a young adult with a closed head injury secondary to a motor vehicle accident, sports injury, or fall. Brain damage caused by anoxia, poisoning, and encephalitis may have similar physical and functional effects and much of what can be said of TBI applies to these pathologies. Unless it is specifically included, this definition excludes cerebrovascular accident (CVA), which has in many respects a different clinical presentation.

Historical Overview of Brain Injury

Changes in personality and behavior after brain injury had been known as clinical phenomena at least since the 1860s. However, before the turn of the century, severe brain injuries were usually fatal, often as a result of postinjury infection (Boake, 1989). During the 20th century, major advances in the treatment of brain injury have typically occurred in wartime. After both the First and Second World Wars, the major combatants had to treat large numbers of injured servicemen and develop neurosurgical and, in some cases, rehabilitation centers to cope with the return of these persons from the front line. Unfortunately, after demobilization, these centers were not maintained.

Many of the pioneers of neurosurgery and what would currently be termed neuropsychology developed new ways of thinking about brain functioning after work with large groups of injured servicemen. Among these pioneers were Kurt Goldstein in Germany, Ritchie Russell in the United Kingdom, and Alexander Luria in the Soviet Union.

Up to the late 1960s, little was known about the long-term effects or natural history of brain injury. In the 1950s and 1960s, many pivotal papers were published. Reports from Davison and Bagley (1969), Lishman (1968, 1973), and others (Achte, Hillbom, & Aalberg, 1969; Hillbom, 1951, 1960) described the long-term psychiatric consequences of severe brain injury. The influence of these studies was accentuated because the findings were based on large series of injured servicemen (Achte et al., 1969; Hillbom, 1951, 1960; Lishman, 1968). The disorders found would in modern nomenclature be termed neuropsychiatric or neurobehavioral. The increasing interest in brain injury also indicated an increased incidence of brain injuries from automobile accidents in the civilian population.

One group of researchers in the new wave of interest in brain injury was led by Bryan Jennett, a neurosurgeon and professor at the Institute of Neurology in Glasgow, Scotland. These researchers developed a far more detailed
natural history of severe brain injury than had hitherto existed (Bond, 1975, 1976; Brooks, 1972, 1975; Brooks & Baddeley, 1976). It is important to note, however, that this group followed patients who were not provided with rehabilitative services. The data were primarily intended to assess outcome from acute management (i.e., neurological intervention). Much of the initial work focused on changes in status on intelligence tests. Patients appeared to recover fastest in the first 6 months, with most of the recovery taking place within 12 months of injury. Later Jennett and his group produced an influential series of papers describing the neurobehavioral effects of severe brain injury from the relative's perspective (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981). Cognitive, behavioral, and personality changes were far more frequently associated with long-term functional disability and family stress than were physical aspects of handicap. Jennett and coworkers found that caring for a person with brain injury was extremely stressful for relatives.

An important countermnemonic finding was that some persons with severe brain injury appeared to get worse as time progressed. It is noteworthy that these early studies emphasized psychological and behavioral status rather than functional status. As already stated, the sample was naturalistic in that patients were not exposed to rehabilitative efforts.

At about the same time that the Glasgow group was developing a natural history of TBI, other groups were developing treatment programs. Comprehensive rehabilitation efforts for persons with brain injury as a discrete group were pioneered in Israel in an attempt to meet the needs of servicemen injured in the 1973 Yom Kippur War. The project was a collaboration of the Israeli defense ministry and the New York University Institute of Rehabilitation Medicine (Boake, 1989). Other projects beginning at about this time included the Center for Comprehensive Services, which opened in Carbondale, Illinois in 1977. A day program at New York University using a primarily social learning model of rehabilitation was opened by Ben-Yishay in 1978 (Ben-Yishay, Diller, & Ratsok, 1978). In 1979 the Kensingley unit, the first specialized unit for behavioral disorder after brain injury, was opened in the United Kingdom (Eames & Wood, 1985a, 1985b). Despite these examples and some other notable exceptions, early attempts at TBI rehabilitation often focused on cognitive rehabilitation with little or no attempt to relate the rehabilitation to real world functioning. It was during the late 1970s and early 1980s that most of the institutional growth in brain injury rehabilitation took place.

Before 1980 there had been no analysis of the learning capacity of persons with brain injury, a factor now considered central to functional rehabilitation. In 1980, Miller published a controlled study of persons with severe brain injury that showed them capable of learning a novel psychomotor task with transfer of skills to a related but different task. From his research, Miller extrapolated that the same types of retraining methods used successfully with persons with mental disabilities (e.g., task analysis and sequential cuing) might be applied successfully to persons with brain injury. Since that time, more basic research into cognitive processes of persons with severe organic impairments has indicated that, despite profound memory deficits, significant learning can take place through learning mechanisms often left relatively intact after injury (Goldstein & Oakley, 1985; Squire, 1986). In the mid-1980s, the first reports of functional skills training efforts with patients with TBI emerged (Goodman-Smith & Turnbull, 1983).

Since then, these concepts have been applied and developed primarily in the United States and an increasing amount of treatment research has been devoted to learning theory-based interventions regarding aspects of functional skills (Giles & Clark-Wilson, 1988, 1993; Giles & Morgan, 1989, Giles & Shore, 1989a, 1989b). Behavioral control (Burke, Wesolowski, & Tave, 1988; Giles & Clark-Wilson, 1993; Zemke, Wesolowski, Burke, & McQuaid, 1989), and social skills training (Brotherton, Thomas, Witoszek, & Milan, 1988; Gajar, Schloss, Schloss, & Thompson, 1984; Giles, Fussay, & Burgess, 1988).

In the mid to late 1980s, community-oriented rehabilitation services were introduced for persons with brain injury. These transitional living centers (TLC) were designed to assist with the adjustment from hospital to community living. The best of them were conscious of their debt to therapeutic communities, and so maximized the effects of social and interpersonal skill development in their day-to-day activities. For many workers the TLC was considered the endpoint in service provision in the continuum from the original injury to community reintegration. It was not until the early 1990s that long-term care for the increasing number of survivors of severe injury was recognized as a pressing need (Jackson, 1994; Jacobs, Blenick, & Sandhorst, 1990).

The Status of Brain Injury Treatment

Structural Changes in Service Provision

Virtually nonexistent as a distinct entity in the early 1970s, brain injury rehabilitation had become big business by the late 1980s. Growth of knowledge and new treatment methods fueled the market. Early treatment pioneers were in demand at commercial enterprises to train staff members in how to treat patients. With the growing number of survivors of brain injury, long-term care has also been recognized recently as a major issue. The current period of contraction of brain injury services is the product of many factors. Only a small proportion of those who require rehabilitation or postacute services actually receive them. Only persons with workers' compensation insurance, with litigation claims, or with extensive private insurance typically receive adequate rehabilitation services. There is a systematic bias toward underserving the underinsured from the emergency room on (Fife, 1987). Even in the cases of patients with private insurance, the growth of managed care has in many cases led to scrutinization of outcomes, and there is considerable pressure to treat patients in the lowest cost environment available (Jones & Evans, 1992). Patients are being discharged from acute care and rehabilitation hospitals earlier and the length of time in transitional living units (when this service is provided) has been decreasing.

The pressure for cost containment has occurred alongside failure to demonstrate a consistent effect of rehabilitation in well designed controlled studies. Unfortunately, along with a lack of robust evidence of treatment effects (see
below), there is strong evidence that some specialized providers of brain injury services have pursued a policy of systematic fraud and abuse (Committee on Government Operations, 1992). Capitalizing on a new and comparatively unregulated division of health care services, these unscrupulous companies have used up patient resources, often providing inappropriate services and discharging the patient the moment that the patient’s insurance coverage or other financial resources are exhausted (Committee on Government Operations, 1992). These types of business practice lead to skepticism about brain injury rehabilitation among regulators and third-party payers.

What works in the treatment of persons with brain injury? In the last 20 years, rapid progress has been made in our understanding of how to help persons recover from brain injury, retreats from a number of blind alleys notwithstanding. In this period of rapid change, it is important to remain focused on effective intervention. It is not adequate to show that patients who have been treated improve; the passage of time and spontaneous recovery might account for the change. To demonstrate a treatment effect, it is necessary to show that the patient improved to a greater degree, improved faster, or is less likely to relapse than a patient who received a different treatment or no treatment at all.

Although occupational therapists work in all areas of service provision, the following discussion emphasizes areas that are central to the focus of occupational therapy Assessment is central to the development of adequate treatment, however, due to space limitations, this overview focuses on treatment rather than assessment issues.

Prevention

Brain injury remains a major cause of death and severe injury (Pickard & Czosnyka, 1993). However, the last 20 years have seen clear advances in accident prevention. Rigorously enforced drunk driving laws in conjunction with targeted public education campaigns are effective in saving lives (Decker, Graifer, & Schaffner, 1988; Giles & Clark-Wilson, 1993). The introduction of passive restraints such as seat belts (O’Day et al., 1988) and air bags significantly reduce mortality and severe injury (Zador & Ciccone, 1993). The introduction of mandatory helmet laws for motorcyclists and bicyclists has been shown to significantly reduce mortality and morbidity (Van Houten, Bolinder, Malenfant, & Van Houten, 1994). Rapid evacuation from the scene of injury (Baxt & Moody, 1987) and the introduction of designated trauma centers have significantly reduced mortality; this pattern is being followed in other countries (Klauber, Marshall, Toole, Klawon, & Bowers, 1985; Ornato, Carren, Nelson, & Kimball, 1985).

Early Treatment

The widespread introduction of neuroimaging techniques and advances in management of intracranial pressure and complications of severe brain injury have led to greater numbers of survivors (Servadei, Piazza, Seracchioli, Pozzati, & Gaist, 1998). Increased recognition of brain injury has led to fewer instances of overlooking brain injury in patients with multiple system trauma (Davidoff, Morris, Roth, & Bleiberg, 1985). The possible effects of mild brain injury and the risks associated with multiple brain injury have also been recognized. There is now significant evidence of the complicating effects of alcohol, both acute intoxication and long-term abuse, on recovery from brain injury (Brooks et al., 1989).

The development of the coma arousal teams in the early to mid-1980s and the subsequent development of coma stimulation programs (National Head Injury Foundation, 1990) was stimulated by research that suggested that certain types of specially structured stimulation could accelerate recovery from coma (LeWinn, 1980; LeWinn & Dimancescu, 1978). Unfortunately, these findings have not been replicated by others (Rader, Alston, & Ellis, 1989). Some practitioners have suggested that an environment with low stimulation may be more conducive to recovery from coma (Ruddock, 1991). The disagreement in treatment recommendations appearing in the literature indicates a lack of consensus in the field (Giles & Clark-Wilson, 1993).

Aggressive neuromuscular management of the comatose patient is practiced in many trauma centers. Range of motion, positioning, and the application of splints and casts may help prevent soft tissue contractures. Serial casting has been shown to result in clinically significant improvement in lower extremity use in the acute recovery period (Conine, Sullivan, Mackie, & Goodman, 1990). The effect of casting on hyper-tonicity requires further investigation (see this issue).

Early Acute Rehabilitation

Although its effectiveness seems obvious to most occupational therapists working in the field, there is little evidence that acute rehabilitation affects recovery from brain injury. The most important questions to be answered are: “Does therapy affect outcome?” “When should therapy be initiated/discontinued?” “Is one form of therapy more effective than another?” There are no well controlled prospective trials available on whether acute brain injury rehabilitation affects outcome. The belief that those who receive rehabilitation early will have better outcome is widespread among practitioners, but there is little well controlled research on human subjects that addresses this issue. A study by Nowak and co-workers (1984) on patients after CVA found that time since injury did have a small effect on response to treatment; however, they noted that treatment has to be delayed by years rather than days before there is any appreciable effect. A study by Cope and Hall (1982) did address this issue in persons with brain injury and found a poorer outcome associated with delayed initiation of rehabilitation. Unfortunately, the study was carried out retrospectively and has significant methodological flaws (see Giles, 1994a). The results of studies comparing types of intervention have been more straightforward. When specific types of physical or cognitive rehabilitation have been compared, no effect unique to any one type of treatment has been found (see Giles & Clark-Wilson, 1993).

Late Acute and Postacute Treatment Phase

In many ways, studies of intervention are easier to conduct and interpret in the late acute and postacute phase of
rehabilitation than in earlier phases of recovery. Spontaneous recovery has slowed to the point that a specific treatment effect may be evident. Prigatano and coworkers (1984) reported on the effect of a 6-month intensive postacute rehabilitation program for young adults with severe traumatic brain injury. Subjects were rated significantly better in terms of psychosocial adjustment and marginally better in neuropsychological measures than subjects in the control group. Eames and Wood (1985a) examined the efficacy of a specialized unit approach to the treatment of behavior disorder by using a comparison group of those who had been accepted to the program but who did not participate. The mean interval between injury and admission to the unit was 4 years and the condition of each patient on admission was considered static. Interventions were a token economy and specifically tailored behavioral control and skill building programs. The results showed improvement in behavior and subsequent placement. There was no trend towards relapse as time from discharge increased, nor was length of time since injury a factor that reduced response to treatment.

Most work done in the late acute and postacute period has involved small group multiple baseline designs and single case reports. These types of studies are less authoritative, due to a greater likelihood of error and reduced external generalizability (i.e., the fact that it worked with a small number of subjects does not mean that it will be more generally effective). Nevertheless, this type of study is increasingly recognized as a legitimate scientific undertaking (Wilson, 1987).

Certain aspects of perceptual retraining, particularly in the area of neglect, have been shown to be effective. The excitement generated by computer based cognitive rehabilitation (Glascott, 1985) has been shown to be largely unfounded, though computers may be a useful adjunct to other forms of treatment. Although well designed studies have usually found attentional retraining ineffective, there are suggestions that certain very structured approaches may be worthy of further study. The type of memory retraining conducted through the 1970s and 1980s involving direct practice of memory tasks has largely been shown to lack positive effect (Giles & Clark-Wilson, 1993). Although early workers were able to demonstrate treatment effects in highly controlled laboratory conditions, it became evident that these improvements did not generalize into other contexts or become integrated into real world skills. The current focus is on having persons with brain injury deal with to-be-learned information in different ways, and to use aids such as notebooks and diaries. Rehabilitationists have developed greater sophistication in encouraging patients to apply the methods they have been taught to real life situations (failure to do so had been a frequent problem with the first attempts at cognitive retraining). The area of functional skills training encompasses a vast array of different interventions from continence training to riding public transportation. There is now a large body of evidence that specifically structured and tailored approaches may have powerful effects in remediating some of these problems.

Social skills training has been the subject of considerable recent study. This area of work is of special interest because of evidence that persons with brain injury may experience increasing social isolation as time from injury increases (Thomsen, 1985). Application of the type of standard model of social skills training used widely with other populations seems to be ineffective with patients with TBI (Johnson & Newton, 1987a, 1987b). There is, however, both individual and group study evidence (using some robust designs) that behaviorally defined and energetically pursued interventions may be effective in both reducing unwanted behaviors and increasing socially skilled interactions (Brotherton et al., 1988; Giles & Clark-Wilson, 1993). Considerable ingenuity has been expended to try to reduce inappropriate behaviors. Many of these efforts have been shown to be effective; learning theory-based approaches are generally the most effective (Giles & Clark-Wilson, 1993).

Studies of intervention regarding return to work have largely been group studies that have included data on the number of persons who were able to return to work and the number of persons able to sustain employment through time. A number of models of vocational intervention are currently in use. Unfortunately, the studies do not use control groups and cannot be directly compared to each other because of significant intergroup differences.

Over the last 10 years, the needs of persons with brain injury and their families have been recognized to continue long beyond the acute recovery period. Specialized postacute services such as transitional living centers have proliferated, but there are no controlled trials of their efficacy. The long-term needs of persons with brain injury and their families are being recognized (Jacobs et al., 1990). The burden of support on families may be extreme (Livingstone, Brooks, & Bond, 1985). Many persons with brain injury need ongoing social and emotional support, whereas others require ongoing community support or long-term care. Family support has been recognized as an important need (Williams, 1991).

Conclusion

Over the last 20 years, important progress in the understanding of the nature and consequences of severe brain injury has been made. Currently the pattern of service provision to persons with brain injury is changing. It is important to keep in mind what we have learned during this period of rapid change. Acute medical management has advanced and more persons with brain injury are surviving. Most rehabilitation workers are convinced of the importance of energetic management in the acute recovery period. The status of acute rehabilitation has suffered in part from economic factors but also from an inability to demonstrate a treatment effect. Despite the lack of strong evidence of a positive treatment effect, we do know that the effects of not intervening are disastrous for both the patient and the family. We know that services in the late acute and postacute phase of treatment should be functionally, behaviorally, and socially oriented. Increased understanding of attention and memory processes are suggestive of new and more helpful ways to structure therapeutic experiences. Specific task training, behaviorally oriented social skills retraining and behavioral control retraining, when carefully selected and obsessively applied, can affect meaningful aspects of real world functioning. Patients are moving out of acute rehabilitation hospitals and into community reentry programs earlier. Lengths of
stay in these programs are also becoming shorter (Jones & Evans, 1992). Many or these patients are still on what we might consider the acute stage of the curve of recovery. From a historical perspective it is evident that relapse or deterioration may be a very important issue for some patients with brain injury. Also critical is the transfer of relearned function into real life performance. One trend of interest that has both advantages and disadvantages is for patients to be seen by therapists at home. Assessment and treatment in the home environment increases ecological validity but provides decreases opportunities for the patient to experience 24-hr assessment and the effect of being part of a therapeutic community. Finally, we know that many persons with brain injury require very long-term treatment and support. We know that psychosocial outcome for persons with brain injury is often terrible and the fact that the patient is neurologically damaged does not prevent a major psychological response to injury. As we move into a rapidly changing health care environment, a historical perspective can help us to be informed advocates for the needs of persons with brain injury.

About This Issue of AJOT

In this issue, we have drawn widely from various stages in rehabilitation and the recovery process. Many of the needs and opportunities for research and service provision are touched on or elaborated on in the articles that follow.

The paper by Kageyama, Imagase, Okubo, and Takayama (1994) is among the first papers describing attentional and radial neglect. The subjects of the study are patients with CVA, but the paper is included because of the importance of the subject and because these deficits were first highlighted in the population with acquired brain injury. Descriptions of attentional and radial neglect have only recently begun to appear in the literature (Butters, Evans, Kirsch, & Weisman, 1989; Menneenneec, Wettman, & Heilman, 1992; Rapcsak, Cimino, & Heilman, 1988; Shelton, Bowser, & Heilman, 1990) and this paper greatly advances our understanding of the relationship between various types of visual neglect syndromes. Many therapists will want to begin including testing of vertical and radial neglect in their testing batteries. This paper does not attempt to relate the inattention to functional impairment, but the authors suggest that vertical neglect may actually be the cause of some problematic patient behaviors often encountered in rehabilitation.

The paper by Coster, Haley, and Banyza (1994) examines longitudinally the sequelae of mild to moderate brain injury in very young children. Their results suggest that there may be a small subgroup of patients who experience lasting injury-related difficulties. Further research in this area is clearly called for.

The paper by Hill (1994) describes a comparison of casting to traditional techniques in treatment of upper extremity motor disorders after brain injury. Hill’s findings suggest that casting is more effective than traditional techniques in reducing contractures and decreasing tone but that superiority on these indicators may not translate into greater functional use.

Nestadt (1994) discusses perceptual retraining for adults with brain damage and suggests that assessment may help delineate the patients most likely to respond to a particular approach. Concrete assessment recommendations are provided.

Avory-Smith and Dellarosa (1994) provide an overview of approaches to the treatment of dysphagia in persons with brain injury and highlight the extent to which more research is needed in this area. The contributions of Haller, Zasler, Maurer, and Cash (1994) on role change are central to the focus of occupational therapy and explicate some of the stresses on the patient and family in the aftermath of severe injury.

Giles (1994b) describes some of the factors that contribute to a person’s response to severe brain injury. The concept of illness behavior is used to explain the responses of two patients whose symptoms could not be explained with reference to neurological impairment alone.

Jackson (1994) emphasizes the need for long-term support services for persons with brain injuries. Various service provision models are described and emphasis is placed on bridging building within the local community. The limited availability of services is seen as a major health care crisis.

Kasowski provides a first-person account of a family member of a person with brain injury. The process of coming to terms with this all-too-frequent human tragedy is discussed in terms of Kubler-Ross’ stages of terminal illness. We are reminded that this is a cyclical and not a linear process.

The contribution by Katzmann and Mix (1994) confirms and extends some of my own work in training persons with brain injury to wash and dress (Giles & Clark-Wilson, 1988; Giles & Morgan, 1989; Giles & Shore, 1989). Katzmann and Mix suggest that practice, rather than practice combined with consistent social and tangible reinforcement, may be sufficient to produce major functional changes in some patients.

Poluski and Emmett (1994) examine the interaction of pharmacological intervention and functional skills training. Their work suggests that pharmacological intervention and functional skills training used in combination may result in improvement in function that would not be possible if either approach were used in isolation.

Badomski provides a useful taxonomy of cognitive rehabilitation and argues that occupational therapists must become more active both in shaping the field of cognitive rehabilitation and in defining our professional role in it.

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