Why Provide Community Support for Persons With Brain Injury?

The papers by Schwartzberg and Schulz in this issue of AJOT were accepted for the March 1994 Special Issue on Brain Injury Rehabilitation but could not be included because of space limitations. They are published here as a follow-up to that issue.

Although it is recognized that persons with brain injury need continued services after discharge from the hospital, remarkably little empirical work has been published about community-based support services (Giles, 1994). Many long-term difficulties of the person with brain injury are associated with increased social isolation. Although functional skills are important in both patient and family view of rehabilitation outcome, the quality of patients’ interpersonal relationships is also important (Tate, Lutham, Broe, Stretles, & Pfaff, 1989). Persons with brain injury are known to have difficulty maintaining preinjury social relationships and developing new friendships (Tate et al., 1989; Thorsen, 1984). Recent work has indicated that even persons without global intellectual impairment may demonstrate major social skills deficits (Spence, Godfrey, & Knight, 1995). Persons with brain injury show increased levels of social anxiety (Newton & Johnson, 1985) and may become increasingly discouraged about their ability to reestablish social ties. Patients may be unemployed and their leisure interests may be poorly defined or nonexistent. As a result the social network of persons with brain injury may shrink. Greater social isolation may also be a factor in the greatly increased rate of psychiatric impairment and suicide among persons with brain injury (Achte, Hillbom, & Aalberg, 1969; Hillbom, 1960). Increased understanding of how socially skilled behaviors break down after brain injury may help in the development of more effective intervention strategies.

Current evidence suggests that the typical social skills training approaches used in psychiatric settings may be ineffective with many persons after brain injury (Johnson & Newton, 1987a, 1987b). Behaviorally oriented programs may be able to affect specific target behaviors such as the elimination of unacceptable physical or verbal habits (Brotherton, Thomas, Wissotzki, & Milan, 1988; Giles & Clark-Wilson, 1993). Although these approaches are effective, they are often extremely labor intensive and may require residential settings (Giles & Clark-Wilson, 1993). Complex social interaction skills are probably dependent on higher cognitive functions such as abstract reasoning, an area in which deficits are common after brain injury (Scherzer, Charonneau, Solomans, & Lepore, 1993). Social skills deficits resulting from impairments of higher cognitive functions are not affected by currently available treatment methods (Brotherton et al., 1988; Giles & Clark-Wilson, 1993). High order social skills involving complex acts of social cognition, such as interpretation of interpersonal situations, may be impaired despite apparent recovery in other domains (Levine, Van Horn, & Curtis, 1993).

Given the limited nature of our ability to help persons with brain injury develop socially skilled behavior, it is necessary to provide patients with continuing community support. Many models for the provision of supported living services are now available for patients who require continuing residential care (Jackson, 1994). Employment in some form plays a central role in facilitating psychosocial integration. Despite improved vocational rehabilitation models, many persons with brain injury cannot gain or maintain lasting vocational placement. Large numbers of patients live in the community, either independently or cared for by family, but do not have ongoing sources of support outside the home. Even patients otherwise classified as having good outcome may require ongoing emotional support to maintain functional independence (Tate et al., 1989). A number of community support provision models have been proposed (Cole, Cope, & Cervelli, 1985) but the most widely used is the support group. Recommendations as to how to start and run a support group are available (Blanchard, 1984), but not detailed investigations of support groups and how they function. A study by Willer, Allen, Liss, and Zicht (1991) found that attending support groups was rated higher by women with brain injury and wives of men with brain injury as an important coping strategy. Men, however, placed greater priority on individualistic coping strategies.

The papers by Schwartzberg and Schulz in this issue examine the factors that participants find important in support groups. This focus is both unusual and important, as most research on psychosocial outcome from brain injury has depended on relatives or professional staff members as respondents and has not focused on the concerns of the persons with brain injury. Given the work by Willer et al. (1991), it is interesting to note that most of the participants are women. Socialization, support, and legitimation of members’ experience are important factors in the group process.

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