Illness Behavior After Severe Brain Injury: Two Case Reports

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This paper introduces the concept of illness behavior to occupational therapists working with patients with acquired neurological impairments. The paper presents two case reports of patients with unequivocal severe brain trauma who demonstrated help-seeking and dependency behaviors that could not be accounted for by brain damage alone. Incorporating the illness behavior concept in an understanding of the patients’ behavior difficulties assisted in the development of an appropriate treatment plan and interventions. This paper emphasizes that severe neurological sequelae and illness behavior may coexist in the same patient. Without an understanding of the personality and environmental factors that may influence recovery, rehabilitative efforts may be less than optimally effective.

Some persons with brain injury demonstrate more marked impairments than can be accounted for by their neurological damage. Until the early 1980s, these persons were often considered to be demonstrating “compensation neurosis” or malingering (Miller, 1961, p. 919, 1966); this account has recently been recognized as frequently inadequate. The view that neurological damage is involved in the production of a set of behaviors need not support a view that dismisses social, personality, and environmental factors as irrelevant. Hempel (1961) noted that, in the early stages of the development of a science, interrelated or dependent factors may be thought of as separate. As a science progresses, it becomes possible to consider how separate variables may interact to produce an outcome.

This report introduces illness behavior as an explanatory concept and illustrates its use in the case formulations of two patients in the late stages of recovery from severe brain injury. A case formulation is intended to be a description of the factors that govern the person’s internal experience and behaviors. A case formulation provides a succinct conceptualization of a patient’s difficulties and acts as a guide for treatment planning. Two case reports are presented in which factors other than the severity and nature of the neurological damage were considered important in treatment planning. The two patients described had definite severe neurological damage and no direct financial incentive to exaggerate impairment. Both patients were in the postacute stage of recovery and both displayed behavior that suggested an exaggerated pattern of help-seeking or dependency or both.

The concept of illness behavior can assist in the understanding of dependent and help-seeking behaviors (Mechanic, 1986). It allows incorporation of information on the interaction of neurological state, psychological processes, and social and environmental factors. These factors may include level of distress, personality and coping style, expectations and attributions, and the interference that the patient’s disabilities have on everyday life functioning. Other factors that may influence illness behavior include past illness experience (personal or familial), the accessibility of health care services, and the patient’s ethnic and cultural background. Cognitive processes are central to illness behavior. Environmental events are selectively filtered depending on factors unique to the person. The events develop personal meaning or are integrated into a previously existing schema of meaning for the person (Horowitz, Markman, Stinson, Fridhandler, & Ghannam, 1990). Central to the development of illness behavior may be the patient’s negative appraisal of his or her ability to use other coping strategies (Lazarus & Folkman, 1984). If patients are convinced that they will be unable to function successfully (by their own standards) in their previously established roles, they may be unwilling to give up their illness role.

The aim of the occupational therapist is to help the
patient minimize disability and reassemble preinjury social roles wherever possible (World Health Organization, 1980). A focus on the patient's cognitive appraisal of the injury and its outcome allows occupational therapists to make a nonpejorative examination of the person's phenomenology regarding injury and recovery. Developing a comprehensive understanding of the life issues facing the patient is central to the occupational therapist. Without an understanding of these factors, occupational therapists may fail to help patients change. The assumption that even limited independence is objectively preferable to dependence may obstruct the therapeutic effort. By failing to adequately grasp the injured person's view of reality, the therapist may fail to understand the motivation of the patient in actively or passively obstructing progress. This paper is intended to highlight illness behavior that may affect recovery in a subset of the population with traumatic brain injury.

Case Report 1

Patient 1 was seen on both a residential and day program basis for assessment and treatment at a transitional living center. History of Trauma

Patient 1, a 38-year-old female factory worker without a previous psychiatric history, suffered a severe brain injury at work when her head was caught in a machine press. Because of the crush nature of the injury, normal measures used to infer severity are inadequate; however, coma duration was approximately 7 days. Patient 1 sustained unilateral damage to the fifth and seventh cranial nerves affecting the right side of her face and lost vision in her right eye. She was discharged from acute hospitalization after 10 weeks and spent the following 18 months at home with her mother. At the time of discharge she was reported to have had “mild cerebellar ataxia and moderate cognitive sequelae.” Patient 1 received no specialized rehabilitation or home-based rehabilitation. While at home, Patient 1 deteriorated; she developed a serious depressive disorder and agoraphobia severe enough to prevent her from going out on her own. After treatment with a tricyclic antidepressant and psychotherapy, she showed some improvement; however, she required 24-hr attendant care. When faced with stresses that she regarded as too taxing, she would take to her bed and refuse to do anything at all; sometimes she had to be fed. Although she stated that she wished to become more independent, she was reluctant to enter the transitional living center treatment program. Since her return from the hospital, the patient's relationship with her mother (who was abusing alcohol) had been deteriorating. Admission was precipitated by an incident at the grocery store. In circumstances that are unclear, a large jar of spaghetti sauce allegedly fell on the patient while she was grocery shopping. Although there was no physical injury, this incident led to a 2-day acute hospitalization and convinced the patient's insurance case manager to insist on her admission to the transitional living center.

Family and Social History

Patient 1 was born in Ohio but the entire family moved to California when she was 2 years old as a result of her father's career advancement. Her parents' relationship was stormy. At the worst periods of parental conflict, the patient's mother would take to her bed for long periods with a bottle of vodka (i.e., the patient had a familial model for response to stress). Patient 1's father left when she was 9 years old, and she reported no further contact with him. After her father's departure, Patient 1 was raised exclusively by her mother. Patient 1's adolescence was apparently unremarkable. She was married at age 20 years and had one daughter. Patient 1 separated from her husband 4 years later; she moved back to her mother's house, where she and her daughter were living at the time of her injury. Before the injury, her work history was good.

Assessment

Assessment at the transitional living center revealed mild memory and language impairment (patient was unable to follow rapid discourse or group discussion). She was also unable to understand subtle or implied meaning. On the Rivermead Behavioural Memory Test (Wilson, Cockburn, & Baddeley, 1985) the patient's performance was most impaired on delayed recall of a prose passage. In addition, she tended to be rigid and concrete in her approach to tasks. Her functional performance during assessment was strikingly superior to her self-report of her abilities and to her customary behavior. Although she never went out on her own because she claimed to cross streets unsafely, she was found on evaluation to be able to cross complex intersections safely and without difficulty, even when the therapist deliberately attempted to distract her (see Giles & Clark-Wilson, 1992, for a discussion of training methods). She claimed to be unable to do her own shopping and cooking, but she was able to plan, shop for, and prepare a meal for 10 people and required guidance only for budgeting and the type of food to prepare.

Case Formulation and Treatment

Although anxiety played a role in her impairment, the patient was reluctant to give up her view of herself as sick and severely handicapped. Her treatment history subsequent to injury could be construed as attempts to overturn any progress that would have reduced her dependency. She was able to state these factors relatively clearly...
herself (i.e., she stated that people did not understand her difficulty and wanted her to become “too independent”). The aim of treatment was to help the patient develop more functional independence without creating overwhelming anxiety at the loss of her sick role. Therapy therefore included repeated validation of her deficits, which were real; reassurances that she would not be pushed too fast; and a program of functional activities that gradually became more demanding. At the transitional living center, treatment included systematic desensitization for her agoraphobia and gradually increasing degrees of responsibility and independence with training in appropriate compensatory systems (e.g., use of a day planner) to maximize functioning given her cognitive deficits. She was subsequently able to move to her own apartment and live in the community at a considerably reduced level of care. She was also attending a local community college. Two years after evaluation, these gains had been maintained despite occasional brief relapses into more dependent behaviors.

Case Report 2

Patient 2 was seen in consultation for assessment only. She provides an example of a patient (unlike Patient 1) whose posttrauma illness behavior occurs against a background of dependent and attention-seeking behaviors prior to trauma.

History of Trauma

Patient 2, a 35-year-old Hispanic woman, was involved in a motor vehicle accident while driving unaccompanied and intoxicated. She was thrown from the vehicle and was found nonresponsive at the scene. At the trauma center, she was found to be paraplegic with a T6–7 transection and to have severe lung and cardiac contusions. She required intubation and mechanically assisted ventilation. Her duration of coma was not reported but appears to have been at least 3 days. Previous psychiatric disorders included a history of substance abuse and multiple suicide attempts. Records indicated that 5 weeks after injury the patient had made rapid progress in her physical recovery and was reported to have achieved independence in all wheelchair and self-care activities. She received no specialized rehabilitative services or in-home follow-up services. She was seen for assessment 18 months after injury.

Social History

Background information regarding Patient 2 was not available as she denied all recollection of her childhood or her parents and refused to have contact with them after her injury. She was married and had four sons (age range 5 to 18 years) and a 3-year-old daughter. Patient 2 reported that her marriage was stable and committed. At the time of the assessment, she was being assisted by her family to perform all basic self-care activities except self-feeding. She refused to leave the house unaccompanied by a family member. She was able to volunteer at the local museum only because her husband or one of her older sons transported her to and from it. She reported that she could only volunteer for 4 hr twice a week because she was anxious about being incontinent. She had been incontinent of both bowel and bladder function at the museum on a number of occasions and her response to this would be to cry continuously and telephone her husband to come and take her home.

Assessment

Assessment involved a review of case notes, a clinical interview, behavioral observations, objective tests, and observations of performance of a range of functional community activities. On the formal evaluation using the Rivermead Behavioural Memory Test (Wilson et al., 1985), the patient had marked deficits on immediate and delayed recall of a prose passage and on face recognition and had marked difficulty in following verbal instructions. Her symptomatology was consistent with the sequelae of a severe brain injury; however, there also appeared to be elements of exaggeration. For example, she claimed not to remember anything prior to her injury, including her parents and her early family history. (Although cases of almost total loss of personal historical material have been reported, they usually occur after severe psychological stress, encephalitis, or profound anoxia. Patient 2’s symptomatology was inconsistent with these disorders.) Patient 2’s initial presentation was anxious and childlike, particularly when her four sons, who had accompanied her to the assessment, were present. She frequently became tearful and spoke with inadequate air support, which resulted in reduced volume and made her speech difficult to understand. To carry out a full functional evaluation, Patient 2 was asked to perform a number of community activities. These included following a simple route to the local grocery store, crossing the street, doing the grocery shopping, and buying coffee in a local coffee shop. Patient 2 was reluctant to have her sons leave the room and was extremely reluctant to engage in the community tasks required by the examiner. Once she was out in the community, away from her family, a marked change occurred. Her speech became stronger and lost the immature aspect that had previously been so marked. She performed the tasks that she had been assigned in a very competent manner and maneuvered her wheelchair safely, even at busy intersections.

Case Formulation

Some of Patient 2’s adjustment difficulties were long-
standing. There were indications of an established pattern of dependent help-seeking behaviors before her injury and of alcohol abuse at a level that affected her day-to-day vocational and social functioning. As a result of the injury, she had genuine cognitive deficits: memory disorder, high-level language impairments, and poor abstract reasoning skills. She was also paraplegic. The combination of these severe stresses and inadequate personality resources, as well as a family that was used to caring for her before her injury, led to her developing and acting on a view of herself as more handicapped than she actually needed to be. Treatment recommendations involved consultation for her difficulties with incontinence and a gradual increase in time at her volunteer job. It was recognized that dependency played an important part of her life and that she would strenuously resist any attempt to remove it. Family-oriented psychotherapy was indicated.

Summary

As an introduction to the concept of illness behavior, two anecdotal case reports were presented. Both patients had sustained severe brain injury that resulted in lasting neurological and functional impairment. Neurologically based deficits are thought to have interacted with personality and social factors and resulted in a pattern of behavior of more marked impairment than could be accounted for by the late sequela of the brain injury itself. For Patient 1, trauma seemed to initiate a pattern of behavior that she might have learned as a child from her family. Treatment approaches were suggested by including the concept of illness behavior in the conceptualization. After her discharge from the acute hospital, she probably experienced repeated failures and progressive role loss with no other available roles to assume. Patient 1 had a realistic fear that she would fail if asked to assume a fully independent role. Unfortunately, her adoption of a sick role (of which she had familial experience) led to her not being as independent as she could be. The goal of the occupational therapy intervention was to teach Patient 1 the viability of a more independent role while convincing her that she would not be forced to assume full independence, at which she believed she would fail.

In the case of Patient 2, who was seen for assessment only, the illness behavior probably represents a trauma modulated manifestation of a previously existing personality problem. Treatment approaches were suggested by this conceptualization. As she received no rehabilitation, she probably experienced repeated failures and progressive role loss with no other available roles to assume. This led her, like Patient 1, to demonstrate a level of dependence in excess of that dictated by her postinjury deficits. It was not possible to develop an understanding of her behavior on the basis of an analysis of the neurological deficits alone.

It is interesting to note that both patients were discharged home after comparatively brief periods of rehabilitation without transitional care and with only minimal follow-up services. It is possible that a period of inadequate professional support and possible failure experiences contributed to the patients' development of illness behavior. It is now widely recognized that anxiety and role loss are frequent consequences of traumatic brain injury (Tyerman, 1984; Tyerman & Humphrey, 1984). Recently the importance of meaningful role acquisition or replacement in the recovery process of some persons after traumatic brain injury has been stressed (Giles & Clark-Wilson, 1992). The process of role acquisition may become misdirected, such as in the development of illness behavior, and may lead to a major impediment to independence. The study of roles is of particular interest to occupational therapists. Further research is clearly indicated in the explanation of these issues in patients with traumatic brain injury.

References