Psychosocial Adaptation to Disability

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Patients in a vegetative state as well as those with intact higher level functioning can be helped to make a positive psychosocial adaptation to their disability. At all levels of functioning, the goal is to maximize the patient’s interactions with a concurrent increase in feelings of self-esteem.

Rehabilitation professionals, in much the same way as the lay population, often misunderstand the concept of psychosocial adaptation to disability, applying it almost exclusively to those individuals who have intact higher level cognitive processes and are able to communicate and interact with their staff and environment. Although these patients definitely require psychosocial support, it should be stressed that even the vegetative state patient can, in a sense, make a more effective psychosocial or psychological adjustment to disability.

Patients in a Vegetative State

On a rudimentary level, patients in a vegetative state do monitor their environment and will show certain psychological reactions when the environment is changed or their daily routine is affected. Initially this results in separation anxiety, often manifested as depression, weight loss, agitation, skin rashes and skin infections. Quality of life is also affected when an individual is placed in an environment of sensory deprivation.

On a number of occasions, patients with limited supervision and no family involvement have been evaluated in the nursing home setting. The striking similarity in the condition of these patients is noteworthy. In each instance the patient was living in an environment of sensory deprivation, where the curtains on the window and around the bed, as well as the walls, were all the same color; there were no pictures or other visual stimuli in the room. No one came in to talk with the patient, and there was no radio or television left on for the patient to receive auditory stimulation. With no visitors, there was no tactile stimulation. The result was a further reduction in cognitive awareness, a withdrawal on the part of the individual and the emergence of many symptoms of anxiety and depression. In addition, the patients tended to show severe contracture deformities, holding their hands in a fist and closed fashion, their feet hyperextended and their bodies in a fetal position with the knees and arms drawn up toward the chest. Their teeth were in extremely poor condition, and no dental follow-up was provided. Infected ingrown toenails were common, and when the patient was helped to relax and partially open his or her hands, it was clear that the palms had not been cleaned in some time. The speed at which these patients deteriorated and the degree to which their life span was shortened by inadequate care was quite clear. Typically such individuals are found in nursing homes, where the staff simply cannot provide the level of care necessary. Nursing homes are usually geared to providing services to geriatric patients or others requiring substantially less than the one-on-one intensity of medical services required by the ventilator dependent patient. As discussed earlier, private-duty around-the-clock LPNs can be hired to supplement the nursing home staff and aid in the aspects of care for which staff time is too limited.

Patients at all levels of functioning can be helped to make as great as possible a psychosocial adaptation to disability in light of their individual condition, and an appropriate program must be designed and provided in order to meet this goal. For those individuals who are in a vegetative state, the basic approach is to provide a highly structured, closely supervised daily schedule of activities with little flexibility for change. The patient needs tactile, auditory and visual stimulation as regularly as possible, and the daily routine should be constant so the patient can feel secure and comfortable within the environment. Nutritional needs must be monitored carefully and appropriate nutritional
supplements provided in the tube feeding process. Bowel and bladder functioning must also be monitored so that the patient is not lying in waste products. This is essential to avoid complications such as decubitis ulcers and to maintain the minimal quality of life that every individual is entitled to enjoy.

**Patients with Higher Level of Functioning**

For the patient with intact higher-level cognitive processes, making a healthy psychosocial adaptation to disability is far more complicated than for the patient in a vegetative state. Supportive psychological counseling must be given, though one or two hours per week is usually not enough to help the patient attain and maintain a maximum level of functioning. These individuals also need the support of family members who have been taught to recognize the various signs and symptoms of psychological distress and trained to provide appropriate support. Staff members should also keep these symptoms in mind and provide behavioral reinforcement as needed.

Little research has been done on the psychosocial adaptation of ventilator dependent patients; nevertheless, many of the same basic principles that apply to individuals with other disabilities can be applied to them. The primary goal of these principles is to help the individuals become as independent as possible. This may be accomplished by encouraging them to make their own decisions, to use technological aids and to develop avocational interests.

**Gaining Independence through Decision Making.** These patients should be involved in decision-making, particularly as it relates to their own well-being but also as it relates to other members of the family. Having their advice sought and showing interest in their thoughts and their concerns will play an important role in the patients' adaptation. In addition, it is essential that patients have some control over their own lives and not have all decisions made for them simply because they are physically unable to carry them out. Individuals who feel that they have lost control of their own lives will often respond by exerting negative control over those aspects of their lives that cannot be controlled by others. Most commonly, they may vent their frustration by verbally abusing staff or family members, or they may fail to cooperate in any manner, such as refusing to eat, failing to control their bowels or withdrawing.

**Gaining Independence via Technological Aids.** Many devices are available to help ventilator dependent individuals control their environment. Environmental control units that are manipulated with chin controls or mouth sticks (sip-and-puff controls) allow patients to run many electrical and electronic devices in their homes. With these devices, they can independently make local and long distance telephone calls, turn the television, radio, and record player on and off; adjust volume and change channels, change temperature settings on thermostats and, if appropriately set up, even open window curtains. Although these devices may not seem to be necessary when patients are twenty-four-hour-awake nursing care, they are actually of significant benefit because they allow patients more control over their own environment; they no longer have to ask someone to perform a service and then wait until it is done. Use of these services can have a very positive psychological impact on patients, relating as it does to their adjustment to disability and development of a daily routine.

**Developing Avocational Interests.** Patients need a sense of purpose and a reason for awakening every morning. A recreational therapist might be needed to help in the development of meaningful avocational pursuits, as patients are frequently unable to engage in the same leisure activities they pursued before the injury or onset of illness.

Individuals with a high level of intellectual functioning can benefit from voice-activated computers, which are now quite reasonably priced. These computers allow their operators
to do everything from playing computer games to participating in budgeting and financial management, balancing the checkbook and other related activities. Keeping patients intellectually stimulated and involved in the daily family routine is an essential part of helping them adapt to their disability.

In a 1984 study, Green, Pratt and Gigsby looked at self-concept among persons with long-term spinal cord injuries. They found that individuals who perceived themselves as having achieved the highest possible level of independence with respect to their level of lesion scored the highest self-concept levels on the Tennessee Self-Concept Scale. When patients reported that they felt as though they had no control of their own lives, they scored on the lower self-concept levels and were seen to have achieved a less satisfactory level of psychosocial adaptation to disability.

In summation, one cannot simply provide supportive counseling or behavior modification to help patients make a good psychosocial adaptation to their disability. When the rehabilitation professional is selecting a clinical psychologist or preferably, a rehabilitation psychologist to provide supportive counseling and behavior modification programs for these patients, it is essential to choose one who is knowledgeable about the disability and the specialized needs of the patient. These services must be provided in the context of a total environment and a total program, designed to help patients achieve a maximum level of independence and participation in daily family activities and personal decision making.

Works Cited: