

INTRODUCTION

Rehabilitation of persons with neurological disabilities is a unique medical specialty. Its uniqueness is partly attributable to the fact that many rehabilitation programs place an emphasis on working with families. Traditionally, medicine has focused primarily on meeting the direct needs of patients.

Within the rehabilitation process, continuing family education regarding the effects of illness and treatment methods is often stressed. Ideally, attempts are made to avoid medical jargon and explain problems and solutions in understandable terms. Theoretically, greater understanding enhances family members' coping ability and enables greater participation in the rehabilitation process.

Because many forms of disability are chronic, participation of families in treatment planning and implementation is frequently encouraged. Ultimately, the long-term burden of care is likely to fall on family members, who may have few available community resources. In many settings, family members are looked upon as integral parts of the interdisciplinary team. Ideally, emphasis is placed on early family intervention and long-term follow-up in the community.

Neurological disabilities are inherently unique. Injury and illness often affects diverse components of the central nervous system. Family involvement in the rehabilitation process is especially important for patients in whom brain functioning has been affected. Memory impairment, intellectual decline, and perceptual problems, along with behavioral abnormalities, typically affect the patient's ability to fully participate in the treatment process. Questions often arise regarding the patient's competency to carry out activities of daily living. Incompetency may require family members to help make important treatment, financial, and life care decisions.

Unfortunately, in many cases patients' self-awareness is limited not only by psychological factors, but by neuropathological factors as well. Clinicians often observe that patients with the most severe brain dysfunction have the least well preserved self-awareness. Concomitantly, they are highly dependent on family members.

Disability and dependency pose great burdens, especially on immediate family members. Ironically, the psychological suffering of family members may be far greater than that incurred by the patient. Undoubtedly, many professionals have acknowledged the need to consider the widespread impact of disability on members of the immediate and extended family. The needs of children, grandparents, and siblings have recently been accorded greater importance along with those of spouses and parents. Support services, including family therapy, individual counseling, and peer support groups are often available and serve as an important adjunct to the overall rehabilitation process.

We believe that families have a valuable role in rehabilitation, and that meeting the needs of family members is often at least as important as meeting those of patients. Because of these beliefs, we have dedicated this issue of *NeuroRehabilitation* to providing an overview of family reactions to neurological disability, family assessment strategies, and intervention. Suggestions are given for involving families in the rehabilitation process and for meeting psychosocial needs. Each author focuses on a specific illness or disease entity. The organization of topic areas is intended to help the reader develop an understanding of the similarities and differences among disability categories.

Each illness or disease entity has unique characteristics that influence the family's reactions and nature of participation in the rehabilitation process. These characteristics include chronicity and disease progression, functional manifestations, extent of brain dysfunction, availability and nature of medical treatment, and patient age. A variety of factors aside from disease characteristics also influence family coping and rehabilitation outcome. These include historical coping style, pre-injury or pre-illness level of functioning and roles, availability of community supports, availability of extended and immediate family members, and financial stressors. The interaction of factors is often complex and changing, which further adds to the challenge of helping families.

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