
Working with Families of Head-Injured Patients

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Family counselling is an essential activity for all members of the head injury rehabilitation team, not exclusively for clinicians with specialized training. While these specialists are necessary, no therapy discipline can work successfully in isolation from each other or from the patient's family. The goal of this article is to help speech-language pathologists and other therapists work with families through the rehabilitation process. We first present general guidelines that can be followed in all rehabilitation settings, from acute care to community re-entry. The remaining sections are used to present guidelines for specific rehabilitation settings, with emphasis on early stages of rehabilitation.

General Guidelines

All families of head-injured patients have some general needs in common. The most important of these needs are for emotional support and for information. In addition, some families will also need professional family counselling.

Emotional Support

There is now a consensus that family members are not bystanders to head injury but victims who have their own problems and need for treatment. Many studies have confirmed that many family members show symptoms of emotional distress, including anxiety and depression, that do not completely resolve with time (Brooks, 1984).

The therapist's response to the family's emotional distress should be to support the family's emotional adjustment and to avoid undermining it, even unintentionally. The essential factors in being emotionally supportive are to be *trustworthy*, *hopeful*, and *accepting*. Each of these points deserves explanation.

In order to be *trustworthy*, the therapist must:

- earn the family's respect as an expert who is committed to reaching the best possible outcome,
- earn the family's loyalty by making sure their questions, complaints, and concerns are consistently addressed, and
- earn the family's confidence by telling them the truth and keeping them informed.

In order to be *hopeful*, the therapist must:

- never rule out the possibility that the patient can improve and/or have a better quality of life,
- never give the impression of having "given up" on the patient, and
- always report a balanced assessment, including the patient's strengths and accomplishments as well as problem areas.

Finally, in order to be *accepting*, the therapist must:

- listen to the family's feelings and opinions without judging them to be inappropriate,
- show understanding that the family is experiencing incalculable stress and emotional pain, and
- be tolerant of ways that the family may react to stress, such as by losing emotional control, threatening staff, and making unjustified complaints.

Therapists who follow these guidelines will be in a better position to form a therapeutic alliance with their patient's families. This alliance can relieve some of the stresses placed on families and can gain their support of the rehabilitation enterprise.

Providing Information

Unfortunately most people, including most family members, are relatively uninformed about brain injury. Family members don't know what to expect of the head injury survivor and don't know what role to take. When family members are well informed, however, they can play an indispensable role at the patient's main advocate in the lengthy recovery process. With proper understanding, the family can make informed choices among treatment options, evaluate services, and make realistic plans. For this reason, the education of families to be successful advocates is an essential part of rehabilitation, not an addition to it, and family education is part of every therapist's job.

Therapists can contribute to family education by:

- inviting the family to participate in treatment sessions where possible,

- explaining therapy and assessment techniques,
- assigning the family tasks to work toward therapy goals between sessions,
- sharing reading materials prepared especially for families, and
- holding educational classes for groups of families.

The family's understanding of head injury is limited by emotional factors, especially during the early stages of the patient's recovery. During acute medical care, for example, some families are afraid to ask about the patient's long-term disabilities (Thomsen, 1987). How should therapists balance between the family's desire for information, on the one hand, and their willingness to accept information, on the other?

Surveys of families during acute care reveal that their main concern is for accurate and timely information (Mathis, 1984; Mauss-Clum & Ryan, 1981). When families are retrospectively surveyed about their acute-care experiences, their chief complaint is that they were not adequately informed (Thomsen, 1987). Thus the greater danger appears to be giving families too little rather than too much information. This approach does not imply that families cannot hold opinions different from the therapist's but only that the therapist's information should be made clear to the family. The therapist's responsibility to the family is to tell them the truth.

Another potential problem is that staff members may give information that is inconsistent or contradictory. Families are usually unsure which staff member is qualified to answer a particular question, and inconsistent answers tend to reduce the family's confidence in professionals in general. The best way to avoid inconsistency is the team approach of continuously sharing information and coordinating treatment between therapists. Therapists must make every effort to avoid providing information that is within another discipline's area of expertise. Inconsistency and conflict cannot be eliminated, but they can be handled without further reducing the family's confidence in the staff. If a family complains about a staff member or about receiving inconsistent information, the best response is usually to first investigate the problem and follow up with the family only after doing so. The worst response is to criticize staff members to families. For the same reason, therapists should avoid criticizing the staff of other rehabilitation centers.

Professional Family Counselling

Because adjustment to head injury is difficult for most families, the ideal solution would be for each patient's family to receive professional family counselling. Unfortunately, few families or rehabilitation centers have the resources to make this possible. Thus it is the responsibility of other therapists to identify which families are most in need of counselling by specialized professionals.

Although this decision is not always clear, it is possible to state some general rules about the kinds of family issues that should be referred to professionals. First, spouses of head-injured patients should routinely be referred for counselling (Zeigler, 1987). In our experience, counselling is usually welcomed by spouses and is often extremely helpful. A second problem in which family counselling may be needed is a serious conflict between family and staff members. This will often include consultation with staff members involved in the conflict. Another problem that warrants intervention is a conflict between family members that impacts adversely on the patient's morale or progress (e.g., parents disagreeing about the need for continued inpatient treatment). Finally, family members should be referred for counselling when they engage in self-destructive behaviors, such as neglect of their personal health. Like family education, family counselling should be considered an integral part of rehabilitation if only because it helps prepare family members to be more effective advocates for the patient.

The above guidelines provide a general basis for therapists working with families in all rehabilitation settings. However, the relative emphasis placed on emotional support and providing information should change as the patient moves to different settings. Because family needs change with time, therapists need to alter their approach to families accordingly. The following sections present some guidelines which can be used in a variety of rehabilitation settings.

Family Needs in Various Rehabilitation Settings

Acute Medical Care

The central issue facing families during the acute stage is often whether or not the patient will survive. Most families under such massive stress can do no more than cope on a day-to-day basis. The routine of home life is shattered, and family members may spend most of their time in the hospital, abandoning outside obligations. The family feels helpless and dependent on medical staff, who are seen as having complete control over the patient's welfare. Family members cling to hopeful signs of recovery and may come to doubt the staff's expertise after the patient survives a poor initial prognosis. Most families are unaware of the long-term consequences of severe brain injury and some believe the comatose patient will suddenly "wake up" as if from sleep (Romano, 1974).

Because families are experiencing such high levels of stress, the therapist's approach should emphasize emotional support. This does not imply that providing information is unimportant, but only that it is premature to begin education and training for long-term issues. In fact, most families wel-

come updates about the patient's condition and notification of changes in treatment.

The speech-language pathologist's role usually begins with assessment once the patient is stabilized. The therapist is advised to contact the family during the assessment stage to interview them about the patient's responses and observe them interacting with the patient. Once treatment begins, the therapist should maintain communication with the family about the patient's progress and appropriate family interactions. Some of the most important topics to advise the family about are:

- the difference between voluntary and automatic or reflex movements,
- the need for modified feeding procedures for the dysphagic patient,
- the need to speak to the patient in an age-appropriate manner,
- how to provide appropriate cognitive and language stimulation,
- how a tracheostomy interferes with vocalization, and
- use of alternate means of communication.

The patient's stay in the acute care setting may be brief and contact with the family may therefore be limited. However, for patients who require continued rehabilitation, the therapist may play an important role in advising the family about rehabilitation options.

Inpatient Rehabilitation

When the patient is transferred to an inpatient rehabilitation center, the family's main focus changes from survival to recovery. Unfortunately, recovery from severe head injury is difficult to predict. Therefore, the family may sustain unrealistic hopes in a complete recovery. During the early phase of inpatient rehabilitation, the therapist's approach should continue to emphasize emotional support. The speech-language pathologist's initial assessment should include an interview with the family about their observations, interactions with the patient, short-term goals, and immediate concerns. Information about the patient's personal interests and important life events should be collected to assure that treatment tasks are familiar and meaningful to the patient and family.

Differences in family coping styles become more obvious once therapy begins. Families of patients who are recovering rapidly may feel that they have "beat the system," anticipate full recovery, and ignore subtle deficits. Families of patients who are progressing slowly may look for quick cures or blame the lack of progress on the patient or staff. Other families work together with the patient and staff, dealing with frustration, setbacks, progress, and rewards as they come.

Family Education

As soon as family members are willing, therapists should facilitate family education and training. Arrangements should be made for families to meet with the therapy team after the assessment period, near discharge, and at regular intervals through the inpatient stay. Having the family participate in speech therapy sessions is a good idea for several reasons. It is usually the best way to demonstrate the patient's abilities and disabilities, establish a common framework for discussing the patient's behavior, and model appropriate ways to communicate with the patient.

Every inpatient rehabilitation center should conduct family education classes in which family members can build their knowledge about brain injury and rehabilitation. At Dallas Rehabilitation Institute, for example, the family education course includes eight classes on the following topics:

1. Overview of the brain and head injury
2. Medical complications and treatment
3. Stages of recovery from head injury
4. Movement problems and therapies
5. Speech and swallowing difficulties
6. Cognitive deficits and cognitive remediation
7. Behavior changes and family adjustment
8. Discharge issues and community re-entry.

The course is scheduled for one evening per week and rotates through the above eight-week schedule of topics. Each class begins with a presentation by therapists, followed by ample time for questions and discussion.

In working with families of patients with persisting communication or swallowing disorders, the speech-language pathologist should provide information and instruction in areas such as the following:

- use and acceptance of augmentative communication,
- changing family communication methods to compensate for the patient's language problems, and
- understanding and complying with non-oral feeding methods or modified diet levels.

Readings for family education on these topics are described at the end of this article.

Support Groups.

Many families benefit from attending support-group meetings with families of other head-injured patients. A support group differs from an educational class in that it has no formal agenda, so that families will feel free to discuss their emotions and experiences. Such meetings can start lasting friendships between families who can profit from each other's experience and support. Every family should be encouraged to join the

Texas Head Injury Foundation (THIF), whose local chapters hold support groups that patients and families can attend after discharge from inpatient rehabilitation. The THIF is the state chapter of a national advocacy group, The National Head Injury Foundation. For additional information see "Family Education Materials" in the Appendix.

Outpatient Rehabilitation

The outpatient therapy program is a transition from the rehabilitation center to the community. Some patients can return directly to productive activity such as work or school. However, for patients who are not ready to resume productivity, the need for continued rehabilitation may be obvious, while the rehabilitation goals may be difficult to establish. For these patients, the family must take an active role in goal-setting and in accessing community services. The therapist should provide as much information as possible in order to help the family advocate effectively.

Unfortunately the stresses created by discharge from the rehabilitation center to home prevent some families from succeeding in the advocate role. After discharge, providing care and daily structure is the responsibility of the family. The patient's need for supervision may be so great that the primary caregiver cannot maintain a job or other duties outside the home. Relationships within the family may be distorted by the changed roles (Lezak, 1988). Because of the risk that the family may burn out, the therapist should have regularly scheduled communications with the family and should watch for "danger signs" such as:

- increased absences or tardiness,
- decreased functional communication skills,
- decreased emotional control,
- preference to discuss problems rather than work on therapy tasks, and
- venting of family anger at the patient or therapist.

These signs should alert the therapist that the family may be experiencing difficulty continuing the rehabilitation process and that a change in strategy may be needed. The family may have encountered obstacles in accessing services. In some cases, referral to an alternative rehabilitation program may be in order. Some rehabilitation centers in major cities offer outpatient cognitive remediation programs for survivors with potential to resume productive activity in the short term. In some centers, day programs are available in which survivors can attend outpatient therapies and remain under supervision through the day. With time, families may become more open to the option of admitting the survivor to a transitional living program. Therapists should become familiar with available post-acute programs in order to make appropriate referrals.

School Services

Although many head-injury survivors are of school age (Frankowski, 1986), there are few guidelines to help families, educators, or therapists working in the schools. For the family, the transition into the school may be a difficult time. It represents a new cycle of applications, assessments, and terminology. It often requires building trust in new staff and learning the rules of a new "special education" system. A first step toward easing this transition is for the family, therapy, team, and school special education staff to meet together to plan the patient's return to school (Savage, 1987).

The role of the speech-language pathologist is to continue with family education so that the family can become the student's best advocate. The family's advocacy role is crucial to ensuring that the survivor receives the most appropriate services. The therapist's approach should again balance information-giving with emotional support. Some of the important areas to advise families about are:

- the importance of their advocacy role,
- the student's right to receive appropriate education services,
- how cognitive and language problems will affect classroom performance, and
- how changes in the student's frustration tolerance and behavior patterns may effect his interaction with staff, family, and peers.

In addition to ARD (Admission, Review, and Dismissal) meetings there should be a consistent communication system between family and staff. Possible methods include interim conferences to bring the family up to date, communication logs, and a buddy system where a teacher aide or student ensures that necessary assignments are taken home.

Additional guidelines for working with families of head-injured students can be found in books by Rosen and Gerring (1986), Savage and Pollock (1985), and Ylvisaker (1985). Therapists can also refer to special issues of the *Journal of Head Trauma Rehabilitation* (1986, 1987) that address pediatric head injury and educational, vocational, and social reintegration.

Conclusion

Head injury to a spouse, child, friend, or family member brings stress to the entire family unit. Clinicians from all disciplines must deal proactively with the day-to-day stresses placed on families after head injury. Across all treatment settings, the essential components of working with families are emotional support and information-giving. The nature of the therapist's informational role changes as the patient moves through the rehabilitation system. It is necessary for therapists in all settings to continually educate themselves and other staff about

the consequences of head injury. They should become acquainted with techniques for patient and family advocacy to help break down barriers to providing appropriate therapy for the family as well as for the survivor. Lastly, therapists should support and educate families and survivors to help them become their own best advocates.

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Appendix

Family Education Materials

Two excellent booklets for educating families about head injury were written by Texas rehabilitation professionals and are published by the Texas Head Injury Foundation. The two booklets are *Head Injury: A Booklet for Families* and *Comprehensive Rehabilitation of the Head-Injured Person*. Both are available from the Texas Head Injury Foundation, P.O. Box 541206, Dallas, TX 75354-1206. A large mail-order catalog of family-oriented materials about head injury is available from the National Head Injury Foundation, 333 Turnpike Road, Southborough, MA 01772.

A useful booklet for families about dysphagia is *Swallowing Disorders: What Families Should Know*, by T. Rader and B. Rende (1988). The booklet is available from Communication Skill Builders, 3830 E. Bellevue, P.O. Box 42050, Tucson, AZ 85733. A good family handout about speech and language disorders is *Impairment of Communication Following Severe Head Injury*, by D. Malkmus. Copies can be ordered from the National Head Injury Foundation. With some additional discussion and education, families of patients with language disorders may benefit from reading books about aphasia. A good example is *Communication Breakdown of Brain Injured Adults*, by H. Broida (1979), available from College-Hill Press, 4580-E Alvarado Canyon Road, San Diego, CA 92120.

Many families will benefit from learning about other families who have suffered a head injury. The following is a list of such books, some of which are available in public libraries:

- Dickenson, M. (1987). *Thumbs up: The life and courageous comeback of white house press secretary Jim Brady*. New York: William Morrow & Co.
- Mahanes, F.F. (1985). *A child's courage, A doctor's devotion*. White Hall, VA: Betterway Publications.
- Rickett, F., & McGraw, S. (1981). *Totaled*. New York: William Morrow & Co.
- Warrington, J.M. (1983). *The humpty dumpty syndrome*. Winona Lake, IN: Light and Life Press. (Also available from: Humpty Dumpty Syndrome, 1125 Old Hickory Lane, East Lansing, MI 48823).
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