Home and Family: Problems and Payoffs
A Panel Presentation and Discussion

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Newhoff

As speech pathologists we recognized some time ago that the occurrence of CVA and a subsequent communicative deficit is an event of crisis magnitude for not only the patient but for the family members as well. Many authors have pointed out the numerous ways in which family life is simply not the same as it was prior to the traumatic event. Postonset the patient and his/her family members are confronted with life styles that are significantly altered. We've all observed that the amount of disorganization which occurs varies greatly among families, but a certain amount of disruption is bound to occur.

Prior to the stroke, families evolve to a point of balance within their unit. It is recognized that this balance may be different in type and degree among families. Such stability has been termed "family homeostasis" (Satir, 1967) and reflects the state of complemental roles and communicative interactional styles of the family. Further, as noted by Webster and Newhoff (in press), roles and communication may change due to such factors as children leaving home or the aging process in general; but the gradual nature of these changes allows for adjustment. Consequently, the family's homeostasis remains intact.

Sudden onset of stroke with resultant disability, however, precludes such gradual adjustment by family members. In such cases both interaction and homeostatic balance are disrupted. If as clinicians we understand this disruption, we cannot be surprised when both patients and their families continue to "exhibit reactions long after the acute crisis has passed" (Webster and Newhoff, in press).

It is the case, therefore, that post trauma the family's homeostatic state is different from that prior to the onset of a communicative disorder. A new sense of balance can be acquired, however, and as clinicians we have recognized the need to intervene in this regard. Linebaugh and Young-Charles (1978) have addressed the family's need for information and Malone

(1969) highlighted the family's need to discuss attitudes and emotions which are alive as a result of the patient's impairment. Additionally, Webster (1977) has noted that clinicians are able to receive information from families that can be of assistance in planning treatment programs for patients. Each of these notions are reflected to some degree in the various options we have available for intervening with families of aphasic individuals. For it is no longer a question of whether or not we should intervene with families. Rather it is a question of in what ways and to what degree.

It seems that traditionally our intervention centered around individual conferences with one or more family members. Indeed, individual conferences are vital because each aphasic person's needs, symptoms and family are unique. More recently, however, group work with families has evolved as a means to supplement individual conferences. Because they may serve somewhat different purposes, families may benefit from both. Current intervention programs include those whose primary purpose is to provide information, to receive information, to assist in problem solving and/or to improve family members' abilities to communicate with the aphasic patient.

The particular intervention program we choose will depend on a number of factors. Obviously, while most of us would agree that we should approach each family as unique, our personal philosophies regarding families, aphasia and intervention will of necessity color our decision making process. Some more basic considerations include the clinical setting in which we operate, the ability of family members to attend, indeed the number of hours in the day. In the best of circumstances our task is not an easy one. Families present us with problems that can thwart progress of the most conscientious, honest, and well-intentioned clinician.

Thus it appears to me that the relationship between the clinician and the aphasic individual's family is symbiotic in nature. If we proceed from the assumption that family intervention can benefit not only the family but the aphasic patient as well, then it is simply a case of our needing them and their needing us.

The presentations of the following participants reflect both problems and payoffs of family intervention. Additionally their discussions reflect the myriad of factors which contribute to our decisions for intervention. It is hoped that the information to be imparted is thought provoking as well.

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The Joint Commission on Hospital accreditation requires that all team members participate in patient planning conferences. Our Veterans Administration Medical Center Neurology Ward Conferences are held weekly and Rehabilitation Conferences are held bi-weekly. New admissions are discussed and discharge planning, although tentative, begins immediately. The possibilities for each patient are: 1. transfer from Neurology to the Rehabilitation Ward for longer hospitalization, 2. discharge home as before, 3. discharge to the care of family or friends different from earlier living arrangements, or 4. discharge to a nursing home.

Obviously there are many advantages to the patient and family from early contacts with the Speech Pathologist, including decision making in regard to discharge. Unfortunately, it has not been rare for patients who stabilize quickly to be discharged without our knowledge. This is more likely to occur when patients have no hemiplegia. We are aware of our obligation to see that they and their families know that something can be done and, in our setting, we seek out the family promptly.

Families tend to visit frequently soon after hospitalization and the Speech Pathologist in acute care settings such as ours may meet the family prior to evaluation of the patient's communication deficits. The Speech Pathologist who stops at the patient's bedside to speak to the patient, to inquire sincerely about the spouse's welfare as well as the patient's, and to discuss communication problems after the stroke, is regarded as a caring professional.

The first contact establishes open communication for future counseling sessions and paves the way for families to discuss their needs. For example, recently a wife who had been at her husband's side daily since his stroke, expressed apprehension about leaving him to attend their son's high school graduation. Their home was 200 miles away. She was shown how to indicate her absence on the calendar to her severely aphasic spouse and how to utilize gestures and graduation momentos upon her return. Her concerns were minimized and both appeared to weather the separation well.

Families tend to be better historians soon after the onset of the brain damage. Information obtained early may be more accurate than when tempered by time, especially concerning the patient's pre-insult personality.

Another advantage we've found is that other team members can utilize information the Speech Pathologist gleans as well as results from the communication assessment in their planning. Often the Speech Pathologist secures more complete background information than physicians and social workers obtain. This may take the form of psychosocial history or language analysis. What may appear as normal language behavior to non-Speech Pathologists, but represents a change according to the family, warrants investigation and may arouse suspicion of diffuse brain damage and possibly require intervention by psychology.

Interaction with other team members also establishes the Speech Pathologist as a vital and dedicated co-worker.

The sooner the Speech Pathologist intervenes, the more time the family has to understand, to accept, and to begin coping.

Comprehensive counseling early lays the framework for what may be years of interactions between Speech Pathologists and families of aphasic patients.

My remarks this afternoon will be related to intervention with families of the severely involved aphasic patients. The professional setting is a community hospital and convalescent center serving a population of approximately 70,000 persons in a university town in an agricultural region of southern Indiana. Many of the persons seen initially in the hospital return to their homes in outlying areas from which transportation is a problem with regard to ongoing therapy.

My initial rehabilitation problem, however, is the physician, usually a general practictioner--but sometimes even a neurologist--who unilaterally decides that the patient needs no therapy. Often this is the end of the matter! The physician, through his "doctor-patient" relationship and his long standing position of high esteem, needs merely to make a simplistic statement about his feeling that therapy will not benefit the patient and the matter is closed regardless of whether the patient has some potential for language rehabilitation. On occasions, however, I do discover severely involved patients who should not be given up "totally" and I can convince the physician and the family that speech and language rehabilitation will be of benefit. Too often I do not see the patient for the first time until well past the optimal period for initiating therapy because the physician's view may be that we shall see how well the patient recovers, then call in the speech pathologist.

When contact is established, a thorough evaluation of the patient is completed and family counseling is initiated. For the severely involved patient, I place more emphasis on treating the family than on direct treatment of the patient. Counseling regarding the patient's status is candid, but cautious. Hope is not destroyed, but undue optimism is not held forth. Initially several sessions are planned with 100% attendance by the most responsible family member present during the evaluation and early therapy. I wish to know firsthand from this relative how well the patient is communicating in his environment and to confront or confirm whether the communication behavior with me is typical of the pattern observed at home. Just as Cheri Florance said in her paper earlier in this present Conference, the quality of the communication may be quite different, depending upon the patient's environment. In rehabilitation we must carefully consider the patient's most practical and readily available means of communicating. Early sessions for these severely involved patients are designed to teach family members how to carry on the most effective communication with the patient at home. We use a pragmatic approach, usually one that is heavily nonverbal for these patients. Sometimes we even teach swearing, facial histrionics, gestures, and intonational variations of their limited and often perseverative utterances to indicate emotional connotations that the patients wish to convey.

With some severely apraxic patients I have used successfully a system of Visual Phonetics which gives the patients pictorial cues for lip and tongue placement, manner of phoneme production and voicing features to help them approximate the words that they wish to say. By having family members understand these articulatory features not only can they help the patient practice at home, but they can more fully appreciate--and interpret--some of the distorted verbalizations that the patient may make.

Family members help design a language board--often a picture board--if it proves to be needed for communication. Family members know best what topics are used in home communication and can suggest the words or pictures most needed to tailor the board to the patient's needs.

If the severely involved patient can read single words, printed words of proper size are used. If reading proves to be poor, then pictures of sufficient size are used. The typical basic board is about 11 inches by 17 inches and contains the most basic needs. Typically the categories included are family members' names, foods and beverages, clothing, household items, basic verbs, numbers, days of the week, and special interest items (hobbies or personal interest activities). If the basic board is not large enough to contain all entries, then additional boards are used. Boards are made of medium-weight poster board. Family members are also taught to use the language board to express themselves nonverbally. Learning to communicate their ideas to me in this way helps them have a better understanding of the patient's point of view as well as helping them to develop patience for the patient.

Family members are encouraged to document problems in communicating and to discuss means of overcoming them with the speech pathologist. Frequently such problems lead me to refer the family member to other professionals for counseling and advice. Other times the problems can be resolved by considering minor changes, such as the patient who no longer wished to be called "Mommie" by her spouse since she had achieved the age of 75 and since no children had been living in the home for more than 42 years. Periodic family conferences uncover problems which are much more complicated, such as potential suicide by the spouse, serious marital problems resulting from lack of sexual drive of the patient, and conflict between the spouse and hired companion for the patient, as the latter developed a strong personal attachment for the daily companion.

Because of the physician's point of view regarding rehabilitation of the severely involved aphasic patient, families often do less than what is best for the patient. Sometimes the family members fear doing things wrong and avoid working with the patient. But by having carefully structured instructions--even for a few sessions--most family members can discover the need for stimulation and come to accept the limited success levels most severely involved patients can achieve. All patients, even the most severely handicapped, must receive the help they need to achieve their greatest potential recovery in communicating.

Webster

There are still professionals who question whether aphasiologists should deal with family issues and problems other than the linguistic ones engendered by aphasia. I contend that the question about whether we should or should not is an irrelevant question. Whether or not we should deal with nonlinguistic family problems, we in fact do deal with them, if only by trying to ignore them and "get down to business." These family problems are apparent, they impinge on all of us who see families, and the problems may dictate, or at least influence, our intervention techniques.

Therefore, I decided tonight to talk about three critical issues faced by many women whose husbands have aphasia. The problems of these wives seem to me to drastically influence our intervention procedures.

My data base is this. In my work, I see family members in a group for one hour weekly for six weeks. During the first meeting I ask the group members, "What are your major problems?" or "What distresses you most about your situation now?" In order to have a second measure of family members' problems, I ask essentially the same question later in the six-week session.

Following is a list of the three problems most frequently mentioned by wives and what I think they suggest for those of us who intervene with spouses. First, wives report problems with having to assume many of the duties formerly performed by the husband. For example, after twenty-six years of not knowing how her husband prepared to visit his income tax accountant, Betty suddenly had to do the preparation. She reported that this was the type of thing that hit her as a drastic and anxiety-producing role change. Income tax preparation is a major once-a-year event, but there are regular nagging duties that wives must perform too. For example there is a real question early after their husbands have aphasia and are incompacitated about how to get the lawn mowed or how to fix leaky faucets in the kitchen. Such problems may be uppermost in a woman's mind at a given time. Aphasiologists are prone to ask wives to do carryover activities at home to assist in their husband's speech therapy. However, if we listen to the wives, we can get a line on who can and who cannot do adjunct speech therapy, or more properly, perhaps, we will get a line on when a wife will be more or less able to cooperate in therapy activities.

The second problem wives report is that they have no time for themselves. These women crave companionship. But they do not necessarily crave the 24-hour-a-day companionship of a dependent husband. Particularly, they are appalled when they have the 24-hour-per-day companionship of a husband who is in many ways a stranger. The women often feel they cannot leave their husbands alone, and they become increasingly frustrated and resentful. If these feelings are paramount in a woman, she is not a good candidate for cooperation with our treatment assignments. Rather, she must be helped to move through such feelings prior to being asked to become an adjunct therapist.

The third problem these wives report is the lack of people to talk to. These women report that they cannot discuss their feelings of isolation with their families or with their neighbors for fear of stirring guilt in family members or appearing to neighbors as bad wives. Often this leaves only other spouses who are in the same boat, or aphasiologists,that these women can talk to. There seems to be ample evidence that when people feel isolated, alone, or frustrated, they may withdraw, or they may argue, or they may behave in ways that can be characterized as uncooperative. Certainly these are not conditions that make the aphasiologist's job easy. There is also ample evidence that when people can ventilate their feelings, communicate about their struggles, and feel that they are understood, they become more able to behave cooperatively.

Therefore I believe we must listen to spouses first and talk to them second. I want to close by quoting a woman who was in our family group while her husband was at the Memphis Speech and Hearing Aphasia Program. I met her in the intensive care waiting room while she was awaiting the outcome of her husband's second stroke. She said of her experience in the hospital "Over here everybody's talking to me; nobody's listening to me." I think it behooves us to listen, not just because we are compassionate people but because listening can also advance our work with aphasic patients.