1989

Stroke rehabilitation : a counseling approach with families.

Thelma Elaine. Wall
The University of Montana

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STROKE REHABILITATION:
A COUNSELING APPROACH WITH FAMILIES

By
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B.A., University of North Dakota, 1984

Presented in partial fulfillment of the requirements
for the degree of
Master of Communication Sciences and Disorders
University of Montana
1989

Approved by:
[Signature]
Chairperson, Board of Examiners

[Signature]
Dean, Graduate School

Date September 28, 1989
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I would also like to extend a special thank you to the Speech Pathology Department at the Seattle Veterans Administration Medical Center - Drs. Robert Miller and George Larsen and Ms. Deborah Livingstone for a truly excellent externship experience.

My deepest and unending thanks goes to my family, especially my father and mother. I thank you for your support throughout my educational career. Your inspiration and belief in me are the source of my strength and my desire to excel.
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</table>
Cerebrovascular accident is a major chronically disabling neurological disease that often radically and permanently changes the lives of its victims (Friedland and McColl, 1987). It remains a major health problem, despite an apparent decline in incidence attributed to improved control of hypertension and other risk factors. About 500,000 new cases of cerebrovascular accident occur annually in the United States alone, of which forty percent are fatal, making stroke the third leading cause of death, behind cancer and heart disease. Thus, approximately 300,000 stroke victims, along with their families, annually face the prospect of rehabilitation from the neurological dysfunction and disability of stroke (Delisa, Miller, Melnick, and Mikulic, 1982).

Physical restoration has long been the primary focus in stroke rehabilitation, with discharge from the hospital and degree of independence achieved in activities of daily living including ambulation, self-feeding, dressing, and personal hygiene used as the criteria to measure the success of rehabilitation (Friedland and McColl, 1987; Niemi, Laaksonen, Kotila, and Waltimo, 1988). More recently, stroke rehabilitation has been redefined to include
development of the patient's maximum physical, psychological, social, vocational, and avocational potential, consistent with physiological and environmental limitations. The goals of rehabilitation programs are to reduce dependence and to emphasize and enhance remaining capabilities. They are not designed to alter or remove underlying neurological damage. Within this framework, it is paramount that, in addition to helping the patient adapt to the environment, the environment be adjusted to accommodate the patient's altered status (Delisa et al., 1982). Family members play an important role in creating a favorable environment in which to facilitate rehabilitation of the stroke victim (Shewan and Cameron, 1984). Primary care providers and/or family members need to be aware of the nature and implications of disabilities arising from stroke. As well, they need to be aware of potential problems that may arise as a result of altered family roles brought about by the disability of a family member (Shewan and Cameron, 1984; Davis, 1988).

As indicated by this brief introduction to the goals of stroke rehabilitation, the focus of any rehabilitation program is holistic treatment of the patient including primary care providers and/or family members. This approach necessitates that the Speech-Language Pathologist expand and redefine his/her role in rehabilitation to include not only
direct patient treatment but also counseling of significant others. By establishing clinical goals that include education and counseling, the Speech-Language Pathologist can facilitate the best communicative environment for the patient and his/her family. Thus, family members can be incorporated into the rehabilitation program in two respects, namely: in assisting the patient in his/her recovery and adjustment and, secondly, in obtaining assistance for themselves in adjusting to the sudden, drastic changes imposed upon their own lives (Davis, 1988).

This paper will develop a two-dimensional view of the family. The family will be viewed as a client needing rehabilitation and as a vital tool or resource needed to facilitate rehabilitation of the patient. This paper will examine an integrated survey of current research and literature in the field of rehabilitation medicine. It will define the psychological and social implications of stroke on both the patient and family. In addition, this paper will elaborate on the environmental factors that promote the well-being and successful adaptation of both the stroke victim and family. Finally, it will examine the grieving process for loss sustained due to illness and disability, with a view to helping both patient and family acknowledge the reality of their loss and deal with their emotional reactions. The end result will hopefully be a family that
is equipped with effective coping strategies to assist in the rehabilitation of the stroke patient.

Communication is a structure that allows individuals to organize and control their environments. Stable family units, and roles assumed by individual family members, are built and maintained through communication. The central issue of this paper is the breakdown of communication within the family due to stroke. In most cases, in order for a patient and his/her family to cope successfully with disability, they need to communicate with each other and with physicians, allied health professionals and counselors. The family may be denied this strategy either initially or permanently due to the nature of neuropsychological deficits sustained by the patient. The stroke victim, as a result, is denied a very vital support system.

A point of clarification will be made at this time regarding the label of aphasia, usually applied to patients suffering impairments involving receptive and expressive language modalities as a result of stroke. The neurological damage of stroke may result in several disabilities including hemiparesis, hemianopsia, dysphagia, motor speech disturbances including apraxia and dysarthria, and bowel and/or bladder incontinence. The neuropsychological deficits that may also arise include the language
impairments, already noted, as well as decreased cognitive functioning including memory, problem solving, and reasoning difficulties, as well as visual-perceptual deficits. For the purposes of this paper, the stroke patient with communication impairments will not be referred to or regarded as having an isolated aphasia. That is, deficits that occur subsequent to stroke are usually multi-faceted and involve not only aspects of communication but also of cognition. This bias is not meant to de-emphasize the devastating effects of aphasia but rather to emphasize the all-encompassing nature of disabilities created by neuropsychological insult.

These critical elements -- the psychological impact on the family system, the grieving reaction to the loss sustained due to illness and disability, and the communication breakdown within the family system -- all interact and will affect any effective counseling session with a family confronted with a stroke victim. Therefore, the end result of this paper is an integration of information from these key elements into a framework for the development of a counseling model that will emphasize the unique role played by the Speech-Language Pathologist in stroke rehabilitation.
Counseling, within the context of this paper, is defined as the sharing of information between the Speech-Language Pathologist and the stroke patient and his/her family with a view toward helping the patient and family cope with their altered circumstances. Counseling, in this paper, does not imply clinical or psychological counseling which is a special field of expertise. The Speech-Language Pathologist's role in counseling the patient and family is justified by his/her agenda of assessing and improving upon the stroke victim's communicative-cognitive stance. Since communicative-cognitive skills represent an interface between neurological, sociological, psychological, physiological and environmental factors, the Speech-Language Pathologist is subjected to concerns about many aspects of the family situation. Counseling is a process that needs to be shared by all disciplines, including speech pathology, involved with the stroke patient and is most effective when it is a link between all disciplines, serving as a framework for all contacts with a family by each discipline (Norlin, 1988; Davis, 1988).

Therefore, the model to be presented in this paper is intended to aid the Speech-Language Pathologist to integrate family involvement within the framework of traditional forms of symptomatic speech therapy. An additional goal is for the creative and competent Speech-Language Pathologist to
use this generic model of family counseling with a wide range of family-oriented tasks within the realm of any rehabilitation program.
CHAPTER TWO: IMPACT OF STROKE ON THE FAMILY

Background

The construct of family behavior and its impact on the individual's behavior is a relatively recent development. Until approximately fifty years ago, research and theory building in the behavioral sciences were directed at understanding individual emotions, motives, and behavior. An individual's behavior was thought to be shaped entirely by forces and constraints intrinsic to that individual. During the late 1940's and early 1950's, members of the mental health professions such as Bowen and Ackerman (cited in Chapey, 1988) began to direct their attention to the background of human relationships that coexist along with individual behavior. These authors shifted their viewpoints from the prevailing hypothesis that a person's behavior should be interpreted in isolation to a viewpoint that individual actions are embedded in a complex, interdependent pattern of family dynamics. Their theses stated that autonomous behavior is, in fact, subtly controlled by the actions of other family members (Norlin, 1988).

This ecological perspective suggests that when an individual changes his/her behavior in some way, the changes reverberate throughout all the relationships involving that
individual. Therefore, change has an impact on the individual and everyone surrounding the individual. Several researchers have developed schemas that describe family functioning styles, especially as these relate to changes imposed by chronic illness and disability within a family member.

Family dynamics will be explored in this paper in an effort to understand how the family unit influences the disabled stroke patient. A model will be developed that will demonstrate how the family can function effectively with a disabled member in its midst. As well, the model will show how the family unit can be an active and integral part of the rehabilitation process (Kozy and Tarvin, 1985).

**Definition of Family**

Family can be defined as an interdependent social system of two or more persons, within which its members fulfill certain functions. These functions include promoting individualism and growth and providing a sense of belonging, security, identity, and support to its members (Kozy and Tarvin, 1985). For the purpose of this paper, family is defined as a husband and wife, parent(s) and child or children, an individual and some other relative, or a combination of unmarried adults.
**Systems Theory**

The systems theory is based on the premise that the cause of behavior cannot be traced back to a single source. This model proposes that effects observed have multiple causes. Thus, cause and effect are joined into a recurring inseparable loop. This model can be used to look for ways in which specific relationships between a group of people and events simultaneously influence the behavior of all the components that interact with one another. The group of interacting components, called systems, are held together by a bond created by their interdependency. Within this system, all elements exert some type of mutual influence on one another because each element depends on the others in some way. The behavior of any single element of a system represents a response to the behavior patterns of all the other members of that system, each of which, in turn, also responds simultaneously to the behavior of this individual. Because of the interlocking relationships, any change in the behavior or status of one member of a system causes a change in all the other members (Norlin, 1988).

When examining patterns of behavior between family members using the systems model, we can observe how the family, as a whole, responds to various predictable and unpredictable changes. D. Kantor and W. Lehr (cited in Chapey, 1988) have suggested a taxonomy of boundaries...
surrounding family activities that forms a concept compatible with the systems theory. This framework is useful for generating inferences about family problem-solving styles. This information can also be used to determine how a family will respond to stress and why its efforts may or may not be successful. Table One provides a description of various family functioning styles used to bring order and stability into family relationships.

In the presence of disability, family system functioning becomes unbalanced and upset, with the system attempting to stabilize itself. The family may use its familiar repertoire of coping mechanisms with greater intensity or rigidity, or it may be thrown off balance so completely that its familiar patterns may no longer be sufficient to control the dynamics within its boundaries. This does not imply that the family relationships are necessarily dysfunctional. The family's unique functioning style should be used, rather, to facilitate rehabilitation of both patient and family (Norlin, 1988; Rollin, 1988).

Transactional Analysis

Porter and Dabul (1977), use transactional analysis with its concept of balances in ego states to examine family role changes. The three ego states of adult, parent and
<table>
<thead>
<tr>
<th>Description:</th>
<th>This family style of functioning is characterized by the presence of strong, fixed boundaries and a clear internal structure.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parents are typically separated from children by a clear distinction of rights and responsibilities.</td>
</tr>
<tr>
<td></td>
<td>Parental authority is firm and unquestioned.</td>
</tr>
<tr>
<td>Major Goal:</td>
<td>To ensure stability in family activities and relationships.</td>
</tr>
<tr>
<td>Message:</td>
<td>Implicit messages are transmitted to guide members' behavior.</td>
</tr>
<tr>
<td></td>
<td>&quot;Care deeply, but be composed.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;Persevere, and you will prevail.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;Be integrated.&quot;</td>
</tr>
<tr>
<td>Advantages:</td>
<td>Closed families forge strong alliances and commitments among family members.</td>
</tr>
<tr>
<td>Disadvantages:</td>
<td>Members of closed families have difficulty taking advantage of support outside the family when usual stability is threatened.</td>
</tr>
</tbody>
</table>

TABLE 1

**FAMILY FUNCTIONING STYLES**

(adapted from D. Kantor and W. Lehr cited in Chapey, 1988)
TABLE 1

FAMILY FUNCTIONING STYLES (continued)
(adapted from D. Kantor and W. Lehr cited in Chapey, 1988)

Open Families

Description: There is a strong sense of democracy pervading the activities of open families. Parents and children tend to have equal opportunities to determine allocation of family resources and scheduling of family time.

This family style of functioning operates with boundaries that are flexible, choosing to open or close them depending on the family's mutual perception of its current needs.

Major Goal: The primary goal is adaptiveness.

Message: Specific tacit messages include:

"Share, and don't withhold."

"Persuade; don't coerce."

"Be authentic (yourself)."

Advantages: Open families are able to respond flexibly to the needs of specific situations.

Disadvantages: In situations of sudden unanticipated stress, an open family may stumble due to its rigid belief in its own flexibility.
**TABLE 1**

**FAMILY FUNCTIONING STYLES** (continued)
(adapted from D. Kantor and W. Lehr cited in Chapey, 1988)

Random Families

| Description | The random family operates as a collection of individuals rather than as an identifiable unit, pursuing separate goals, keeping separate schedules, and maintaining separate social networks. |
| Boundaries for these families are never fixed so family members are able to operate with maximum individual freedom. |
| Members cope with personal crises as they deal with their lives in general -- individually rather than collectively. |
| Major Goal | Free exploration for all family members is the goal. |
| Message | "Inspire the others." |
| | "Discover your own potential." |
| | "Be creative." |
| Advantages | In a period of stress as a family, the random family capitalizes on its primary resource: the self-reliance of its individual members. |
| | Because each person is independent, a crisis is unlikely to throw any member off balance. |
| Disadvantages | The pattern of coping individually means members are denied the benefits of family cohesion. |
child are used to describe behavior of both the patient and the spouse.

In the patient, the adult state is often weakened, resulting in reduced ability to examine options, reduced assumption of responsibilities and reduced communication with spouse and/or family members. On the other hand, the child state is often exaggerated with the patient showing increased dependency and feelings of helplessness. The patient may demonstrate ego-involved impulsivity with a continual concern about self. The patient may become overly protective of the spouse, constantly monitoring his/her activities. In some patients, the parent state is weakened with the patient unable to act in a socially appropriate manner as reflected by emotional lability and overuse of profanity.

The spouse may also show a disruption in ego states such as a weakened adult state with concomitant feelings of helplessness and an inability to take control in the face of the disability of a family member. Spouses, especially wives, may tend to overemphasize the parent state, treating their husband as a child by becoming overprotective and mothering.
Studies of Family Function

Evans, Bishop, Matlock, Stranahan, Halar, and Noonan (1987) applied a systematic measure of family function, via a Family Assessment Device, to identify aspects of family that might predict stroke outcome by preventing or promoting adjustment. This measure of family function was compared to baseline ratings of typical predictors of stroke outcome. Prediction ratings given by family members on stroke outcome included variables such as problem-solving abilities, family communication skills, and patient self-care ability. Several family variables were reported as significant predictors of post-hospitalization adjustment and re-hospitalization time. The most significant positive family factor, affective responsiveness, consistently predicted reduced hospitalization time during the ensuing year.

The authors, in discussing the study results, indicated that family functioning represents an area for potential stroke intervention that has relevance to efficient health care delivery and the clinical status of stroke patients. The authors stated that if previously established family roles do not shift with the new role of the patient entering into rehabilitation, there may be conflict and lack of support for independent behavior. They also suggested that some family interactions in the home may sustain dependent behavior and place patients at risk for more than average
periods of re-hospitalization. They concluded that it would be advisable to counsel caregivers to find ways to express feelings openly while avoiding emotional over-involvement.

The effects of family dynamics on stroke outcome are further impacted by problem solving and family communication. Evans et al. (1989) stated that better communication and problem solving are associated with improved patient adjustment. An interesting outcome of this study was the finding that patient self-care ability is negatively related to patient adjustment, and thus, a poor predictor of stroke outcome. The authors reported that merely encouraging the family to be involved in the patient's treatment does not address issues such as family functioning and coping strategies which can disrupt home care and affect patient adjustment. The authors stated that haphazard family involvement may result in adverse outcomes and social deterioration.
Prospective information regarding the adjustment process to stroke and of data comparing pre- and post-stroke social environmental factors related to well-being and successful adaptation for both the stroke patient and his/her family have been lacking. Most reports on the psychosocial impact of stroke have been descriptive and anecdotal in nature or have only gathered information at one point in time, usually months to years after the stroke occurrence. The underdeveloped nature of the psychosocial aspects of stroke is due, in part, to the overwhelming nature of the physical impairments that accompany stroke. Psychosocial impairments are also not as readily apparent as physical impairments. In addition, the negative emotional sequelae of stroke have, in the past, been viewed as primarily reactive in nature. Stroke victims have been expected to come to an acceptance of their condition with the passage of time. Psychosocial adjustment was then expected to follow (Buck, 1968; Artes and Hoops, 1976; Fengler and Goodrich, 1979; Webster and Newhoff, 1980; Rau, Tompkins, Schulz, Rhyne, and Golper, 1986; Friedland and McColl, 1987; Niemi, Laaksonen, Kotila, and Waltimo, 1988).
**Definition**

The psychosocial aspects of stroke that make up the quality of life may be defined as the patient's well-being and life satisfaction. This includes his/her mental and physical health. Also included are interpersonal relationships within and outside the family, work and/or social activities in the community, personal development and fulfillment, and active recreation (Ahlsio, Britton, Murray, and Theorell, 1984; Niemi, Laaksonen, Kotila, and Waltimo, 1988).

**Impact on Patient and Family**

Recent studies have begun to examine the large number of stroke survivors who are affected by psychosocial dysfunction which takes the form of decreased leisure and social activities, even among those stroke survivors who achieve complete physical restoration (Labi, Phillips, and Gresham, 1980; Sjogren, 1982). Reportedly, the most frequent types of functional deficits after stroke are those influenced by psychosocial factors (Evans, Bishop, Matlock, Stranahan, Smith, and Halar, 1987).

The stroke survivor experiences stress from three sources. Firstly, he/she is subject to the same stressful life events as anyone in the general public. Secondly, he/she is subject to the serious illness of the stroke
itself. Thirdly, and perhaps most importantly, the patient is exposed to a cluster of events produced in the aftermath of the stroke. Upon returning home, the individual is confronted with change. This includes changes in functional performance, changes in family roles, changes in social life, and changes in employment status. The events experienced tend to be negative, beyond the individual's control, and unanticipated. This marked increase in total number of stressful life events experienced by stroke survivors places them at increased risk for psychosocial dysfunction (Friedland and McColl, 1987). Depression is a particularly prevalent form of dysfunction among stroke victims (Sjogren, 1982; Feibel and Springer, 1982; Robinson and Price, 1982).

While the factors responsible for psychosocial dysfunction are, in part, attributable to organic etiology (Robinson and Benson, 1981; Gainotti, 1972), the patient's coping style and social resources are also important factors in determining the extent of dysfunction experienced (Friedland and McColl, 1987). While the importance of the family as a key element in the patient's rehabilitation team has been emphasized, the family is also a dynamic social unit, which is influenced in complex ways by the disabled family member. Family roles may change as a result of the emotional, physical, and economic demands imposed by the
disability. A synopsis of the impact that stroke has on the patient and his/her family is provided in Table Two. Role reversals may be accompanied by disagreements over the performance of household and other activities (Carpenter, 1974). Previous studies have reported that the stroke victim's relatives experience particular difficulty in the areas of guilt, unrealistic attitudes, rejection, overprotection, and social withdrawal (Aita, 1947; Blackman, 1950; Derman and Manaster, 1967; Malone, 1969; Turnblom and Myers, 1952; Wepman, as cited in Malone, Ptacek, and Malone, 1970). To some extent, these unhealthy attitudes stem from a lack of accurate information and an unrealistic understanding of the malady and its impact on the family (Malone, Ptacek, and Malone, 1970). These feelings, on the part of care providers and family members, are associated more with changes and instability within the family unit rather than as a result of patient behavior problems (Evans, Bishop, Matlock, Stranahan, Smith, and Halar, 1987).

Spouses of stroke patients are at high risk for depression, as well as other negative changes (Artes and Hoops, 1976; Fengler and Goodrich, 1979; Kinsella and Duffy, 1979). Rau, Schulz, Tompkins, Rhyne, and Golper (1986) studied the social support and well-being changes related to disabling strokes in a sample of stroke patients and their partners. Information was obtained at two points in time --
at four to eight weeks following stroke onset and six months later. They found that almost half the spouses remained at risk for depression at six to eight months after the stroke. These results demonstrate a need for focusing attention on the partner as well as the patient. Another study conducted by J. C. Brocklehurst (as cited in Evans and Miller, 1984) reported a deterioration in the spouse's health to be the primary social effect. He determined that the primary problem in the majority of stroke patients living in the community is lack of support for the lay health provider -- this usually implies the family, especially the spouse.

Neuropsychological Correlates

The concept of mental duress and lack of adjustment of both the patient and family secondary to neuropsychological changes that occur is an area of rehabilitation literature that requires further investigation. L. J. Mykyta (1976) noted that over two-thirds of spouses seeking counseling for stroke-related issues had partners with communication disorders. This suggests that communication and communication breakdown may play a critical role in psychosocial adjustment, perhaps even more so than physical impairment.
TABLE 2
MULTIDIMENSIONAL FRAMEWORK OF THE
IMPACT OF DISABILITY ON THE PATIENT AND FAMILY
(adapted from Kozy and Tarvin, 1985)

<table>
<thead>
<tr>
<th>Patient</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical</strong></td>
<td><strong>Family</strong></td>
</tr>
<tr>
<td>The stroke victim experiences</td>
<td>Family roles need to be redistributed to incorporate</td>
</tr>
<tr>
<td>physical deficits including</td>
<td>changes necessitated by the debilitated patient.</td>
</tr>
<tr>
<td>hemiparesis, dysphagia, and</td>
<td>Family schedules need to be reorganized to accommodate</td>
</tr>
<tr>
<td>bowel and/or bladder inconti-</td>
<td>hospital visitations and therapy regimes. As an outpatient,</td>
</tr>
<tr>
<td>nence, causing decreased</td>
<td>the stroke patient needs increased</td>
</tr>
<tr>
<td>ability to carry out activities</td>
<td>physical supervision with</td>
</tr>
<tr>
<td>of daily living. The patient</td>
<td>bathroom and bathing,</td>
</tr>
<tr>
<td>needs to adapt to changes in</td>
<td>ambulation, self-care,</td>
</tr>
<tr>
<td>routine necessitated by</td>
<td>feeding, and dressing.</td>
</tr>
<tr>
<td>structured therapy programs.</td>
<td>The home environment may need to be modified to accommodate a</td>
</tr>
<tr>
<td></td>
<td>wheelchair.</td>
</tr>
</tbody>
</table>
MULTIDIMENSIONAL FRAMEWORK OF THE IMPACT OF DISABILITY ON THE PATIENT AND FAMILY (continued)

(adapted from Kozy and Tarvin, 1985)

<table>
<thead>
<tr>
<th>Psychological</th>
<th>Patient</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient may become egocentric, reflected in a concern for self which reduces premorbid consideration for the needs and feelings of others. The patient may develop a heightened attention to the immediate present with an intense desire for structured routine. The patient may demonstrate unproductive coping and defense mechanisms. As well, the patient may become insecure and manifest a constant concern for the health of spouse and/or other family members.</td>
<td>The family may harbour unhealthy attitudes about the cause of the stroke and about the family member who has sustained the stroke. These feelings may include: - retributive guilt (Family members may blame or punish themselves.) - irrational beliefs (The illness may be met with belief in miracles, denial, or absolute will-power to overcome.) - rejection (The patient may be treated with dislike or contempt or may be neglected or punished.) - overprotectiveness (The family may fear for the patient's health or reoccurrence of stroke and may overshield the patient.)</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 2

MULTIDIMENSIONAL FRAMEWORK OF THE
IMPACT OF DISABILITY ON THE PATIENT AND FAMILY (continued)
(adapted from Kozy and Tarvin 1985)

<table>
<thead>
<tr>
<th>Patient</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>Families may experience a range of feelings including anger, frustration, helplessness, and anxiety as they try to cope with their unique circumstances as they try to incorporate the stroke victim back into the family milieu.</td>
</tr>
<tr>
<td>The patient may suffer altered and erratic emotional behavior due to the neurologically-based reduction of inhibitory mechanisms. Emotional reactions may include emotional lability — a highly variable emotional response differing in degree and frequency from that shown before onset of the stroke. The patient may also demonstrate catastrophic reaction — an appropriate emotional reaction in kind but of an intensity that exceeds what would normally be expected. As well, the patient experiences feelings which are common reactions to crises of fear, frustration, anger, depression, guilt, and embarrassment (Eisenson, 1973).</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 2
MULTIDIMENSIONAL FRAMEWORK OF THE
IMPACT OF DISABILITY ON THE PATIENT AND FAMILY (continued)
(adapted from Kozy and Tarvin 1985)

<table>
<thead>
<tr>
<th>Patient</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social</strong></td>
<td>The presence of disability can cause interruptions in normal social patterns. Long-term disability and its impact on family structures can lead to social isolation as friends and acquaintances carry on with their normal daily routines.</td>
</tr>
<tr>
<td>The patient may withdraw from social contact due to physical constraints. This may be reinforced or responded to by subsequent withdrawal by family members or even friends.</td>
<td>In addition to coping with illness, additional family stress is experienced by severe demands placed on the family resources. Financial burdens may be increased due to loss of employment and income, increased health and hospital care costs, and lack of adequate health insurance coverage.</td>
</tr>
<tr>
<td><strong>Economic</strong></td>
<td></td>
</tr>
<tr>
<td>The patient is unable to carry out his/her responsibility in contributing to the family's financial resources. The patient's retirement plans may be altered, as well as long-term plans for family economic stability and well-being.</td>
<td></td>
</tr>
</tbody>
</table>
Niemi, Laaksonen, Kotila and Waltimo (1988) studied the quality of life forty-six stroke survivors four years after their first stroke. They utilized a questionnaire that covered four domains of life: working conditions, activities at home, family relationships, and leisure time activities. The results showed that in spite of good recovery in terms of discharge from hospital, activities of daily living, and return to work, the quality of life of most patients had not been restored to pre-stroke level. Subjective tendency to depression was highly correlated with deterioration in the quality of life. Speech disturbances reportedly, had no effect on the quality of life. However, the authors noted that three of nine patients with severe aphasia could not deal with the questionnaire, and thus the authors conceded that their results probably underestimated the impact of communication disorders on the quality of life.

Friedland and McColl (1987) examined the effect of social support as a mediator between stressful life events experienced by stroke survivors and outcome measured by psychological dysfunction. One of the variables they found to be unrelated to stroke outcome was laterality of lesion. They had anticipated a positive relationship between left hemisphere lesion and poor psychological outcome consistent with Robinson and Price's (1982) findings. The authors
accounted for this inconsistency by stating that their study had excluded subjects who lacked functional speech. They further stated that aside from evidence linking aphasia to depression (Robinson and Benson, 1981), an assumption could be made that patients suffering from aphasia experience a decrease in social support due to their diminished ability to communicate.

The research cited above shows the impact that communication breakdown has on both the patient and the significant people in the patient's environment. As Evans and Miller (1984) indicated, the origin of psychosocial dysfunction for stroke patients lies in the discrepancy between what the patient can do and what is expected of him/her by significant others. The situation, they reported, becomes stressful to patients when family and friends fail to alter situational demands or do not psychologically relieve the patient of this discrepancy.

Therefore a need exists to alter the stroke patient's environment to accommodate for cognitive and communicative deficits. To reach this end, the family, as well as the stroke patient, require information and strategies unique to their situation. The Speech-Language Pathologist plays an important role as a counselor and educator in this regard.
The cumulative losses imposed by disability due to stroke usually have profound impacts on a family's relationships and culture. The family and the patient both enter a period of emotional upheaval and adjustment not unlike the mourning period that follows the physical death of a family member. Tanner (1980) adapted his model of the grieving process to include those stages defined by E. Kubler-Ross (1969) to describe the progressive sequence of emotions experienced.

Tanner described grief as the human reaction to loss. In referring to aphasia, he described the loss as consisting of many dimensions. The patient's family feels the loss of a significant person. The patient may experience a loss of some aspect of self due to disability and impairment from the stroke. He/she may experience a loss of external objects such as home and valued possessions when disability results in extended hospitalization or a move to a nursing home. Illness and disability may accompany developmental loss experienced concurrently as a result of the aging process. A loss of security may arise from diminished physical health and altered living situations.
Table Three has been compiled from three sources, namely: the stages of the grieving process as defined by Kubler-Rose (1969); a description of the physical stances that link visible behavioral stances to the stages of grieving, as developed by Satir (1972) and finally, the stages of adjustment to disability as stated by Kerr (1961).

The Speech-Language Pathologist can become a more effective counselor by using information regarding grieving and the adjustment process surrounding disability. Matkin (1988) defined implications with regard to counseling parents of hearing-impaired children. These implications are discussed here as they can be readily applied, with some modification, to stroke rehabilitation programs. Matkin (1988) indicated that families should not be excluded from receiving information or from participating in initial evaluation sessions as this might only serve to reinforce their denial. At the same time, since family members might be unable to assimilate copious amounts of information during the denial stage, feedback should be kept brief after the initial evaluation is completed and a diagnosis is made. The stage of anger with its associated hostility and guilt should be recognized as legitimate, and the family and patient should not be shielded from these emotions. Rather, an accepting climate should be fostered in which the family and/or patient can verbalize and vent their feelings. In
the bargaining stage, the patient and family should not be given false assurances which have little or no validity. In the final stage of acceptance, both the Speech-Language Pathologist and the patient and family should be aware that coping with limitations imposed by the stroke disability is a lifelong process. Unlike coming to terms with terminal illness and impending death, there is no finality.

Professionals and family members involved in the rehabilitation process should be aware of the following pitfalls when considering traditional viewpoints about the grieving stages. Although the grieving stages are clearly delineated in chronological order, this does not imply that an individual or individuals inevitably make all the stated transitions; nor does it imply that the family, along with the patient, will pass through the progressive stages in synchrony with each other. In addition, the family and/or patient may go through the grieving process a number of times during the aftermath of the stroke. Therefore, neither the order nor the rate of progress of emotional resolution is predictable. In some cases, fixation at a given stage may occur, precluding final resolution and the eventual acceptance of the loss incurred (Tanner, 1980; Matkin, 1988).
### TABLE 3

**GRIEF REACTIONS AND THE PROCESS OF ADJUSTING TO DISABILITY FROM STROKE**

(adapted from Kubler-Ross, 1969; Satir, 1972; and Kerr, 1961)

<table>
<thead>
<tr>
<th>Stages of Grieving</th>
<th>Behavioral Strategies</th>
<th>Stages of Adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial - The initial stage of reaction to crises. Characterized by numbness and an inability to think clearly.</td>
<td>Super reasonable - &quot;I don't believe it!&quot;</td>
<td>Shock - A time of uncertainty, fear, confusion, and panic, as well as not knowing what to do. Lack of psychosocial support can result in development of exaggerated fears and ignorance.</td>
</tr>
<tr>
<td>Anger - This stage results from initial realization of the disability, characterized by anger, resentment, and rage, Indifference to and/or lack of cooperation to rehabilitation may be present.</td>
<td>Blaming - &quot;Why me?&quot;</td>
<td>Expectancy of recovery - Typical expectation is that illness is temporary and recovery will be complete. Unpreparedness for the duration and long-term stress implicit in chronic or permanent disability. This phase is characterized by slow discovery of extent of damage and the prognosis for recovery.</td>
</tr>
</tbody>
</table>
TABLE 3

GRIEF REACTIONS AND THE PROCESS
OF ADJUSTING TO DISABILITY FROM STROKE

(adapted from Kubler-Ross, 1969; Satir, 1972; and Kerr, 1961)

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</tr>
</thead>
<tbody>
<tr>
<td><strong>Bargaining</strong></td>
<td>Placating</td>
<td><strong>Coping</strong></td>
</tr>
<tr>
<td>This stage is marked by an attempt to delay the loss or reduce the effects of loss.</td>
<td>&quot;If I work hard and do everything required of me. I will get better.&quot;</td>
<td>Healthy or neurotic defenses may be employed in order to re-establish equilibrium into the family system.</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>Irrelevance</td>
<td><strong>Mourning</strong></td>
</tr>
<tr>
<td>In this stage, the disability can no longer be denied, and anger has been vented. Ultimate acceptance will arise only as the full pain of loss is experienced.</td>
<td>&quot;I give up -- why fight it?&quot;</td>
<td>Realization that life will never be exactly the same. Issue of loss is confronted; change and rebuilding begin to occur.</td>
</tr>
<tr>
<td><strong>Acceptance</strong></td>
<td>Congruence</td>
<td><strong>Adjustment</strong></td>
</tr>
<tr>
<td>In this stage, the reality of disability is acknowledged -- and also its prognosis. Rehabilitation efforts are most fruitful at this stage.</td>
<td>&quot;It's happened. What can we do to get on with life?&quot;</td>
<td>Patient is re-integrated back into the family system of functioning. Roles are redistributed. Disability and the disabled individual are no longer necessarily the main focus or concern of all the family's energy.</td>
</tr>
</tbody>
</table>
CHAPTER FIVE: COMMUNICATION DEFICITS

Traditional Language Programs

Language intervention strategies with stroke patients have evolved as a result of close scrutiny of traditional programs for treatment of communication disorders (Wepman, 1972; Chester and Egolf, 1974; Holland, 1978; Davis and Wilcox, 1981). The goal of traditional therapy programs was to improve the aphasic speaker's linguistic skills through intensive training programs (Yorkston, Beukelman, and Flowers, 1980). The contention under traditional programs was that intensive language therapy should be started as soon after the stroke as possible and continued with the aim of returning the patient's language abilities as close as possible to premorbid functioning levels. The patient was given mental exercises at a particular level of performance and was then slowly advanced toward a higher level of processing. (Delisa et al., 1982). Generally, this approach emphasized the patient's deficits without promoting adjustment or compensation. This type of therapy has been controversial. As Delisa et al. (1982) indicated, by focusing attention on disabilities that cannot be changed by special education techniques, the language retraining process can be detrimental to the patient's recovery. In addition, this type of language therapy clearly cannot
restore the patient's physiological ability to make the complex neurological associations that previously enabled him/her to rapidly process the symbols of language through multiple channels of input and output. The expectation that language can be restored by therapy only serves to frustrate everyone concerned and only interferes with rehabilitation (Delisa et al., 1982).

The traditional model of therapy typically included three elements, namely: 1.) diagnosis of the problem based on symptomatology; 2.) establishment of goals in treatment based on the diagnosis; and 3.) delivery of therapy to the individual in one-on-one situations. In this traditional approach, the involvement of the family tended to be passive, with limited opportunity provided for the family to become active participants in therapy. Families typically received general information about aphasia, general suggestions and/or reading material under traditional programs (Yorkston, Beukelman and Flowers, 1980). Spouses and/or family members, lacking formal training in verbal and nonverbal communication systems, often had difficulty modifying their patterns of communication when confronted with breakdowns in communication. In many cases, family members stated that although they were intellectually prepared for the changes in the patient, they found daily communication attempts to be frustrating and unsatisfactory.

Introduction of Pace

The traditional orientation to language therapy was challenged by Holland (1978). She emphasized the pragmatic component of language as the basis for treatment in clinical aphasiology. Later, Davis and Wilcox (1981) developed a clinical treatment plan based on this premise. Response criterion, in therapy tasks, was established on the basis of the patient's ability to successfully communicate a message. In this method, the patient was encouraged to use whatever medium was most facilitative, i.e. gestures were encouraged as a supplemental communication mode. This approach termed Promoting Aphasics' Communication Effectiveness, (PACE), focused on maximizing the patient's ability to communicate as independently as possible. This method facilitated communication by emphasizing the patient's residual communication abilities (Newhoff et al., 1981).

The basic principle of rehabilitation has been defined in this paper as maximizing the patient's use of his/her remaining abilities. In language therapy, programs need to be designed to allow for utilization of the Speech-Language Pathologist's observations of the patient's remaining communicative abilities and for incorporation of increasing
abilities that may return with spontaneous recovery. To accomplish this, the Speech-Language Pathologist may work to make those responses within the patient's capacity more consistent or efficient; eliminate or reduce any maladaptive communication behaviors; reinforce behaviors likely to produce less stressful interactions and/or present communication situations in which the patient can respond successfully. This intervention plan reinforces the patient's existing abilities as well as encouraging positive gains that are feasible and realistic, given the specific impairments of the patient (Delisa et al., 1982).

Implications for Family Involvement

Just as important as helping the patient adapt to the environment is adjusting the environment to accommodate the patient's communication deficits. Within this context, spouses and other family members of patients are included as integral components of a comprehensive language program. As previously stated in the introduction to this paper, spouses and other family members can benefit from participation in training programs with the goal of facilitating the patient's overall adjustment (Newhoff et al., 1981; Delisa et al., 1982). The final goal of the PACE program is to maximize communication in the patient's natural environment. Researchers, including Wepman (1972) and Wilcox and Davis (1978), stated that communication is an interactive process.
between patients and their communication partners. Therefore, treatment should focus on this process (Yorkston Beukelman and Flowers, 1980).

In this regard, Speech-Language Pathologists need to emphasize three areas, namely: 1.) education of family members and care providers regarding communication disorders associated with stroke; 2.) referrals to agencies or other support systems that are suited to the patient and family level of functioning; and 3.) adjustment of the expectation of others in regard to the patient's ability to communicate (Delisa et al., 1982). Establishing a functionally-based program should help improve the patient's care, his/her quality of life and his/her ability to adjust to his/her surroundings.

Family/Patient Perspectives

The impact of a family's influence on the rehabilitation of the stroke patient has been well documented (Turnblom and Myers, 1952, Bjorn-Hansen, 1957, Buck, 1969 and Malone, 1959). As early as 1951, Wepman commented that the ability of the family to estimate objectively the patient's language contributed significantly to language recovery. Goodkin (1968, 1969) attempted to modify the spouse's verbal interaction with the patient and concluded that the spouse's verbal behavior can either
facilitate or impede the language recovery of the patient (Helmick, Watamore and Palmer, 1976). Flowers, Bottorf and Kelly (1977) and Linebaugh and Young-Charles (1978) all reported a strong tendency for family members to rate functional communication of stroke patients higher than the ratings from Speech-Language Pathologists. Flowers (1977) and Linebaugh and Young-Charles (1981) also found that family members were generally overconfident in their judgements with respect to the patient's communicative abilities. Helmick et al. (1976) reported that family members have unrealistic expectations for the language performance of the stroke patient. They also indicated that family members frequently use inappropriate language when conversing with the stroke patient.

Rolnick and Hoops (1969) and Skelly (1975) reported the following communication problems cited by stroke patients. Comprehension is impaired when family members use lengthy sentences combined with a fast rate of speech. Patients report that family members talk too much, try to talk for the patient, or interrupt in an attempt to anticipate the patient's message. This is problematic for patients who need more time to formulate and produce responses. Malone (1973) and Patterson (1973) stated that patients are mistreated in communication situations. Relatives are at a loss in how to deal with them, shout at them, speak to them
as if to a child, and become overprotective and irritable. Malone (1969) stated that aphasic parents are often ignored by their children. Skelly (1975) reported that stroke patients are aware of and sensitive to nonverbal communication of annoyance by others.

More recent research, such as a study conducted by Linebaugh and Young-Charles (1981) is encouraging in that it demonstrated a new awareness on the part of family members to improve functional communication with stroke patients. Spouses, polled in their study, identified a need to develop improved communication with the stroke patient.
Chapter Six: Counseling the Family

This paper has discussed the serious consequences following the occurrence of a stroke. The resulting illness and disability necessitate numerous adjustments in the patient's premorbid functioning. The family, adjusting to an upset in its balance or homeostasis, due to the illness and disability of one of its members, has also been described. The significant social and emotional consequences that follow in the wake of this upheaval have also been detailed. Within these considerations, the primary goal of rehabilitation has been defined as altering the patient's environment to enhance maximum functioning. A secondary goal of rehabilitation has been defined as helping the patient and family to come to terms with the reality of disability.

Rehabilitation, in this regard, is a combined effort that involves both the patient and family. Family members become crucial rehabilitation team members because they serve as a liaison between the patient and health care professionals. However, family resources can only be effectively mobilized when the family copes with its own adjustment to disability. The counseling model to be presented next will focus on the family per se, without
inclusion of the patient. This bias is presented because the writer believes that the family can benefit from exclusive contact with the Speech-Language Pathologist. This does not imply that counselling sessions cannot be held with patient-family combinations. The symptomatic speech-language sessions held with the patient will undoubtedly include patient-clinician based counseling as an integral part of therapy.

Counselor Functions

Webster (1977) and Webster and Newhoff (1981) have specified four counselor functions which can be served by the Speech-Language Pathologist in his/her interaction with stroke patients which can also be applied to the patient's family. These counselor functions include the following:

1. receiving information that the family wishes to share that might be helpful in the rehabilitation process;
2. providing information to family members;
3. helping family members clarify ideas, emotions, and attitudes and helping them to accept and understand the patient; and
4. providing the family with options for changing communication patterns to facilitate their own, as well as patient, adjustment.

These four components will be examined with a view to defining a counseling role that is congruent with the expertise and responsibilities of the Speech-Language
Pathologist in rehabilitating the stroke patient. As a process, counseling is unpredictable at best, and multiple specific variables that define each family's personal dilemmas give every counseling session a unique flavor. The goal in this paper is to implement the process of counseling in order to arrange interactions between people and relevant issues, thereby creating a context in which a family can solve its own problems (Davis, 1988; Norlin, 1988).

The attached appendices include ideas and agenda items that can be explored and incorporated in organizing counseling sessions. These should be used in a flexible and creative manner by Speech-Language Pathologists.

Obtaining Information

The first counselor function is to obtain information from the family about the patient's communicative environment, family activities and interests that might suggest the semantic content for patient treatment, the patient's communication behavior at home, and the family's own concerns. Even in expressing their own concerns and in asking questions, family members can provide information about their perceptions of the patient's problem, the communication demands on the patient, and the effectiveness of any prior information provided to the family. A questionnaire that is designed to elicit this information is
included in Appendix A, entitled *Family Questionnaire: Communicative Habits of the Stroke Patient* (Norlin, 1988). This questionnaire can be perused solely as a guide by the Speech-Language Pathologist or it can be distributed to family member(s) requiring its completion prior to initiation of counseling.

**Disseminating Information**

In giving information, the Speech-Language Pathologist should interpret the patient's communicative-cognitive disabilities in preparing the family to assist in the patient's recovery. The information provided to the family might include a discussion about the consequences of brain damage, the purpose and results of tests, plans for treatment, and the patient's prognosis. The crucial issue here is that the information provided regardless of amount or content, is understood and accepted by the family.

Travis and Kozy (1985) advocated a psycho-educational approach which included both the provision of information and education through an optimal medium. These are outlined in Appendix C, *Family Education Methods*. Some families learn best by reading and hands-on demonstration. As a result, the Speech-Language Pathologist should assess the family's learning style and provide information that is consistent with the family members' learning style. For
example, families who learn best by experience may benefit from a therapeutic pass or home visit by the patient to illustrate necessary living requirements outside the hospital. The final outcome of this visit could be the feedback the rehabilitation team receives from the family on problems and concerns that need to be resolved during the remainder of the patient's hospital stay. Therefore, all involved parties are better prepared for the patient's eventual discharge back into the community (Norlin, 1988).

**Attitude Clarification**

Through genuine understanding and encouragement, the Speech-Language Pathologist may provide family members the opportunity to have attitudes and feelings clarified. In this regard, the Speech-Language Pathologist needs to be an active listener, acknowledging and accepting concerns. Through the expression and understanding of their feelings surrounding the cognitive-communication deficits of the patient, the family may be able to become more accepting and committed to rehabilitation efforts.

Methods for minimizing dysfunctional family responses to cognitive-communicative impairments are provided in Appendix B, entitled *Methods for Minimizing Family Dysfunctional Responses to Cognitive-Communicative Impairments*. Also included is a description of the
intervention methodologies by DePompei, Zarski, and Hall (1988).

Modification of Communication Behavior

The Speech-Language Pathologist may also facilitate changes in families' communication styles which will have benefits in facilitating an optimal communication environment for the stroke patient. By encouraging and providing the family with suggestions on how to modify their behavior communicatively, the Speech-Language Pathologist can foster increased confidence and independence in the patient (Davis, 1988). Florance (1981) suggested a measure, entitled the *Family Interaction Analysis*, that can be used to study the relationship between the behavior patterns of the stroke patient and his/her communication partner. This measure is presented in Appendix D, *Modification of Communicative Behavior*.

Communication difficulty is often thrust upon the stroke patient and his/her communication partner very suddenly. The communication partner is forced to utilize self-created strategies which he/she hopes will help the patient or at least reduce his/her own frustration. These behaviors often include speaking in a loud voice, repeating, guessing, using very simple sentences, requiring one-word responses, and so forth. As a result, these behaviors can
actually limit the patient's chance for successful communication and/or cause the patient to withdraw communicatively. For example, a non-facilitative communication act from a patient's partner might be an open question such as "What shall we do today?". This could cause a communication breakdown due to the patient's inability to self-generate a response. The communication partner should be counseled on using a more facilitative technique such as providing a stimuli, limited in nature, such as "Would you like to watch television or go for a ride in the car?". This technique could be employed, as Florance (1981) suggested, by having family members make an audio tape or video recording of a home conversation and then bringing this recording to a counseling session. At that time the Speech-Language Pathologist and the family participants could discuss those aspects which promote good communication and those which need refinement to become more conducive to facilitating patient-family verbal interactions.

Counseling Format

Norlin (1988) stated that families often follow an identifiable agenda in adapting and adjusting to the impact of stroke on one of its members. This agenda generally follows the four counselor functions discussed. Once the disability is put into perspective by knowledge imparted,
that have built. The family can then clarify its attitudes about its situation. After dealing with their emotions, the family is able to develop new compensatory communication strategies. Because these elements are interdependent, attitudes, knowledge and skills may all merge in rhythmic cycles over the course of counseling sessions held.

**Group Counseling**

The most widely accepted and utilized counseling intervention as it relates to stroke rehabilitation centers around individual conferences with one or more members of a particular family with a stroke victim in its midst. These individual conferences are vital because each patient's needs, symptoms, and family milieu are unique. However, as Newhoff, Florance, Malone, Ritter, and Webster (1980) stated, group sessions with family members are evolving as a means to supplement individual counseling sessions. Brookshire (1978) stated that family counseling groups, as well as serving to educate families and acting as a forum, allow families to express feelings and learn to adjust to altered roles and lifestyles. Furthermore, groups function as a social outlet and peer support network for families. Some research studies have shown that the group approach to counseling has successful results with families, as well as patient groups (Bardach, 1969; Emerson, 1970; Singler, 1982). Yalom, cited in Luterman (1984) identified a series
of interdependent curative factors in group therapy as these relate to group psychotherapy. These factors, which have wide applicability in counseling groups within the field of communication disorders, are listed and elaborated in Table Four.
TABLE 4
CURATIVE FACTORS IN GROUP COUNSELING
WITH THE COMMUNICATIVELY-DISORDERED POPULATION
(adapted from Yalom, cited in Luterman, 1984)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instillation of Hope:</td>
<td>A patient/family is buoyed up by seeing how other individuals overcome their adversity.</td>
</tr>
<tr>
<td>Universality:</td>
<td>Through group participation, the patient/family recognizes he/she or they are not alone in his/her or their feelings or perceptions.</td>
</tr>
<tr>
<td>Imparting Information:</td>
<td>Information can be provided not only by the leader, although the group can be structured so that the leader provides most of the content, but also by members in the group. Knowledge can be gained by sharing of experiences. Advice-giving can indirectly convey a mutual interest and caring. Thus, it serves as a vital function within a group. The collective wisdom of the group is greater than the knowledge of any one individual alone.</td>
</tr>
<tr>
<td>Altruism:</td>
<td>Related to imparting of information is that participants of the group get a chance to help one another. This helper role enables group members in turn to receive help without a concomitant loss of self-esteem. The desire to help moves group members away from morbid self-absorption, allowing them to grow.</td>
</tr>
</tbody>
</table>

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### TABLE 4

**CURATIVE FACTORS IN GROUP COUNSELING WITH THE COMMUNICATIVELY-DISORDERED POPULATION**

(adapted from Yalom, cited in Luterman, 1984)

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Learning:</td>
<td>The group is a vehicle for participants to enhance interpersonal learning. They learn to be more open and accepting of others. This knowledge can be taken from group interactions into other relationships.</td>
</tr>
<tr>
<td>Group Cohesiveness:</td>
<td>Cohesiveness is tied to trust. When trust develops, growth can occur in groups. Cohesiveness is related to the attractiveness of the group to its members.</td>
</tr>
<tr>
<td>Catharsis:</td>
<td>Catharsis is the expression of the considerable effect surrounding communication disorders. The group can provide a vehicle for release and sharing of pent-up feelings.</td>
</tr>
<tr>
<td>Existential Issues:</td>
<td>Groups give the individual the chance to work through paradoxical issues such as responsibility assumption-dependency, loneliness-love, and meaningless-commitment issues.</td>
</tr>
</tbody>
</table>
CHAPTER SEVEN: CONCLUSIONS

This paper has attempted to define the milieu created by stroke with its resultant impact on the patient and his/her family. In order to better the prospects of the patient's adaptation following stroke, our focus, as Speech-Language Pathologists, needs to be broadened to look at the "whole" person whose life has been altered by stroke, thus leaving behind the stereotypes signified by references such as "the aphasic" or the "aphasic patient". We need to shift our focus of therapy away from attempting solely to reteach those skills and abilities within the circumscribed area of impaired receptive and/or expressive language modalities that the patient may have incurred as part of the debilitating sequelae of stroke. Instead, by focusing on the patient and those significant person(s) in his/her life, we can assess the environment with all of its facilitative and non-facilitative aspects in an attempt to help the patient make the most optimal adjustment, through rehabilitation and within the constraints imposed by residual deficits. This paper has illustrated how the Speech-Language Pathologist can play a counseling role with the patient's family. This role is assumed to take place within a multi-disciplinary framework where open communication occurs not only between the patient and family...
and all members of the rehabilitation team but also between all professionals involved in the provision of care for patient and family alike. It is only within this framework that the Speech-Language Pathologist, along with the patient and his/her family, will find rehabilitation a rewarding and successful process.
REFERENCES


APPENDICES

Appendix A: Family Questionnaire: Communicative Habits of the Stroke Patient (adapted from Norlin, 1988).

Appendix B: Methods for Minimizing Family Dysfunctional Responses to Cognitive-Communicative Impairments (adapted from DePompei, Zarski and Hall (1988).

Appendix C: Family Education Methods (adapted from Travis and Kozy, 1985).

Appendix D: Modification of Communication Behavior (adapted from Florance 1981).
1. When the patient has difficulty thinking of a word, which of the following behaviors does he/she use? (Rank behaviors in order used; 1 is most, 7 is least.)

 ____ Delay
 ____ A sound associated with the word he/she is trying to use
 ____ Use of a word related in meaning
 ____ A description of the word
 ____ A gesture, where possible
 ____ Air-draw a symbol or first letter of intended word
 ____ Abandons attempt entirely

2. When he/she has difficulty understanding a word, which of the following behaviors is used? (Rank behaviors in order in which they are used; 1 is most, 6 is least.)

 ____ Facial expressions
 ____ Asks for repetition
 ____ Offers an earlier response
 ____ Admits he/she doesn't understand
 ____ Makes an accurate but associated response
 ____ Makes an irrelevant response

3. Are there particular types of words which the patient finds easiest or hardest to say? Explain.

4. Is the patient able to give directions? Explain.

5. Is the patient able to respond to directions? Explain.

6. How do you provide directions to complete a task to the patient? Explain.

FAMILY QUESTIONNAIRE:

COMMUNICATIVE HABITS OF THE STROKE PATIENT (continued)

(adapted from Norlin, 1988)

(Adapted from questionnaire developed by Chwat and Gurand, 1981)

8. When you are together with the patient, what types of things do you talk about? Explain.

9. In your own words, how has the patient changed?

10. If a stranger were to visit the patient, how would you prepare him/her? Explain.

11. Explain to me what it is like to live with a person who has communication and cognitive deficits due to stroke.

12. Does the patient communicate his/her troubles, worries, anxieties, etc., to a certain person? Explain.

13. Does the patient initiate communicative attempts or only respond to others' initiations? Explain.

14. How does the patient express emotions such as joy, frustration, anger, gratitude, humor, dissatisfaction, annoyance? Explain.
APPENDIX B: METHODS FOR MINIMIZING FAMILY DYSFUNCTIONAL RESPONSES

TO COGNITIVE COMMUNICATION IMPAIRMENTS

(adapted from DePompei, Zarski and Hall 1988)

<table>
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<tr>
<th>Cognitive-Communicative Impairment</th>
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<th>Family's Dysfunctional Reaction</th>
<th>Intervention Method</th>
<th>Anticipated Family Functional Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor pragmatic skills</td>
<td>She irritates us by interrupting our conversation, and then she talks about something entirely different.</td>
<td>Blaming</td>
<td>Awareness of why behavior occurs</td>
<td>Learn to read non-verbal cues of patient that she wants to speak.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Role playing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Active listening</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX B: METHODS FOR MINIMIZING FAMILY DYSFUNCTIONAL RESPONSES
TO COGNITIVE COMMUNICATION IMPAIRMENTS (continued)
(adapted from DePompei, Zarski and Hall 1988)

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<th>Intervention Method</th>
<th>Anticipated Family Functional Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anomia</td>
<td>He has difficulty saying words, Since I know what he wants to say so I say it for him.</td>
<td>Taking over</td>
<td>Education</td>
<td>Allow patient to communicate on his own.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Modeling</td>
<td>Wait out conversational pauses with patience.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Role playing</td>
<td>Use cues to assist, but don't speak for the patient.</td>
</tr>
</tbody>
</table>
### APPENDIX B: METHODS FOR MINIMIZING FAMILY DYSFUNCTIONAL RESPONSES

TO COGNITIVE COMMUNICATION IMPAIRMENTS (continued)

(adapted from DePompei, Zarski and Hall 1988)

<table>
<thead>
<tr>
<th>Cognitive-Communicative Impairment</th>
<th>Family Description of Behavior</th>
<th>Family's Dysfunctional Reaction</th>
<th>Intervention Method</th>
<th>Anticipated Family Functional Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tangential speech</td>
<td>We won't take him to visit our friends anymore. His conversation is fragmented and makes no sense.</td>
<td>Controlling</td>
<td>Education</td>
<td>Allow patient a choice of participation in social activities. View behavior as not intended to embarrass.</td>
</tr>
<tr>
<td>Poor pragmatic skills</td>
<td></td>
<td></td>
<td>Role playing</td>
<td>View behavior as not intended to embarrass.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Reframing</td>
<td>主动聆听</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Active listening</td>
<td>主动聆听</td>
</tr>
</tbody>
</table>

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(adapted from DePompei, Zarski and Hall 1988)

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<tbody>
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<td>Low frustration tolerance</td>
<td>His temper outbursts are bad. We try to control him and force him to behave. We tend to fight.</td>
<td>Employing power</td>
<td>Rehearsal</td>
<td>Be able to read behavioral signs that frustration level is being reached.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Reframing</td>
<td>Recognize outbursts as not a confronta- tion issue.</td>
</tr>
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</table>
## APPENDIX B: METHODS FOR MINIMIZING FAMILY DYSFUNCTIONAL RESPONSES TO COGNITIVE COMMUNICATION IMPAIRMENTS (continued)

(adapted from DePompei, Zarski and Hall 1988)

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</thead>
<tbody>
<tr>
<td>Inability to express emotional feelings</td>
<td>When he gets depressed and doesn't talk to us, we just go out and leave him alone.</td>
<td>Avoiding</td>
<td>Education</td>
<td>Take cooling off period, but don't blame patient for need to be apart to do other things.</td>
</tr>
<tr>
<td>Feeling responsible for family upheaval</td>
<td>Recognize use of avoidance, but share responsibility for this equally.</td>
<td>Active listening</td>
<td></td>
<td>Allow time for family to share feelings.</td>
</tr>
</tbody>
</table>
APPENDIX C: FAMILY EDUCATION METHODS

(adapted from Travis and Kozy, 1985)

Active Listening: Family members should learn to read such nonverbal messages as inability to attend, desire to speak, or inability to inhibit a response. Videotapes of family interactions with patient would be beneficial in developing active listening skills of family members.

Rehearsal: Family members should be provided with the opportunity to practice responses that they need to utilize with the patient. Actual practice should be similar to situations that occur in the family environment.

Role Play: This is the creation of scenarios by the Speech-Language Pathologist to prompt occurrence of a patient behavior, allowing the family to practice a desired response. The family should be given the opportunity to handle the communication involved. Videotaping various role plays and reviewing them with the family is the basis for learning different responses and supportive behaviors.

Modeling: The Speech-Language Pathologist can provide examples of how to respond by allowing family members to observe therapy sessions and then by including family members in direct participation in therapy sessions.

Reframing: This involves viewing a situation from a different perspective. Instead of a family member focusing on a communicative behavior as intended to anger, he/she needs to see the behavior as the patient's inability to carry out a communicative function. Family members should focus on emerging positive behaviors and maximize strengths, rather than dwell on weaknesses.
APPENDIX D: MODIFICATION OF COMMUNICATION BEHAVIOR

(adapted from Florance 1981)

Analysis of Family-Patient Communicative Interaction Styles

Behaviors of the Communication Partner which are Non-Facilitative

1. Inattentive posture
2. Incongruent affect
3. Lengthy response
4. Self focus
5. Inappropriate topic change
6. Advice giving
7. Judgmental response
8. Premature confrontation
9. Interrupting
10. Guessing
11. Repeating
12. Over-simple language
13. Loud voice
14. Abrupt topic change
15. Speaking for patient

Behaviors of the Communication Partner which are Facilitative

1. Closed questions
2. Verbal following
3. Minimal encouragers
4. Open questions
5. Paraphrasing content
6. Reflecting feeling
7. Summarizing content
8. Summarizing feeling
9. Sharing
10. Confrontation
11. Interpretation
12. Verbal cueing
13. Gesturing
14. Instruction
15. Labeling
16. Modeling
17. Physical cue
18. Request for attention