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THE OPINIONS OF FAMILY MEMBERS  
OF DYSPHASIC PATIENTS CONCERNING  
FAMILY COUNSELING

A Thesis

by

BRENDA YATES

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Submitted to the Graduate School  
Appalachian State University  
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for the degree of  
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August 1985

Major Department: Language, Reading and Exceptionalities

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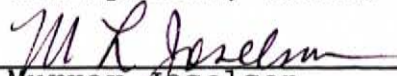
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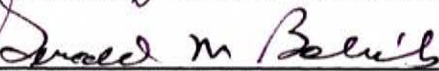
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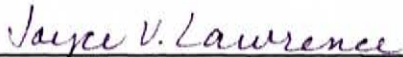
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ABSTRACT

The Opinions of Family Members of Dysphasic Patients  
Concerning Family Counseling. (August 1985)

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Thesis Chairperson: Edward Hutchinson

This study attempted to determine the extent to which the family members of dysphasic patients felt that counseling services met the needs of the family. The primary focus was the spouses' satisfaction with services, including speech and language therapy, rendered in a private hospital.

This was an attempt to give insight into the frequently confronted problem of family guidance as it concerns speech pathologists in hospital and clinical settings. Questionnaires were distributed to family members of individuals who had been diagnosed as dysphasic.

Results indicated that family members did consider some type of counseling to be beneficial in helping them to deal with the changes in family dynamics as a result of the dysphasia. They expressed

opinions as to topics they considered most beneficial for discussion and avenues for possible improvement. In addition, implications concerning counseling, and possible future research were discussed.

## ACKNOWLEDGEMENTS

I would like to express my appreciation to Ms. Ann Hodges and Rex Hospital for their cooperation in the initial stages of this project. I would also like to thank Ms. Dorothy Yates for her assistance in the distribution and return of the instrument.

To Buddy

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## CHAPTER ONE

### Introduction

#### Significance of the Problem

The question of providing family guidance therapy frequently confronts speech and language clinicians in hospital and clinical settings. There currently seems to be a concern among health care providers as to the extent to which family guidance is a necessary component of dysphasia therapy, and who should be responsible for providing these services.

Although only a single individual experiences the physical trauma of a stroke, the related problems involve the entire family. An individual's role as a vital, productive member of a family unit can be abruptly changed by a stroke. This sudden alteration can have direct and indirect effects on the entire family. Often, the people closest to the stroke victim can have the greatest difficulty coping with this sudden and dramatic change in their lives.

The changes which occur in an individual who has suffered a stroke are varied. They may range from mild, temporary dysarthria and slight unilateral

weakness, to total aphasia and complete paralysis. The emotional reaction of the patient and family may be just as varied, depending upon the level of impairment, and there are as many reactions as there are people to experience them.

However, evidence suggests that the family environment can either reinforce and strengthen, or negate and diminish any gains achieved in the therapeutic setting (Helmick, Watamori, and Palmer, 1976). Therefore it is imperative that family reactions and reinforcement be positive. Frequently immediate family members find it difficult to deal with the situation without a support system. It is at this point that some type of professional counseling can be beneficial, if not absolutely necessary.

#### Purpose

The purpose of this study was to determine the extent to which spouses of dysphasic patients feel that the family's and patient's needs have been, or might be, met through family guidance services. The primary focus was the spouses' satisfaction with services rendered, particularly family counseling in the context of speech and language therapy.

Several issues were addressed in this project. The primary question was whether the family received

any type of formal counseling, and, if family counseling was received, the family's degree of satisfaction with those services. Regardless of whether counseling was received, inquiries were made as to the extent to which families considered counseling beneficial. In addition, participants were asked to express an opinion as to whom they felt should conduct these services.

A goal of this study was to examine possible avenues for improvement of family guidance services in the hospital setting. Common patterns of response were considered with regard to possible strengths and weaknesses of services.

#### Limitations

The primary limitations of this study involve the population and the instrument. The population was not chosen randomly, nor was it considered to be representative. This was a descriptive study of the responses of patients' families in a single hospital. Therefore findings may not be generalizable to other populations.

Secondly, the use of a questionnaire format imposes its own limitations. Possibly the most obvious limitation is the minimal amount of control the investigator has with regard to the completion and return of the instrument. Frequently as low as

forty percent of questionnaires are returned (Best, 1981). Although better than half of the instruments from this investigation were returned, the questionnaires that were not returned might have affected the data significantly.

Other limitations concern the questions of validity and reliability. These limitations can be overcome to a great extent through careful construction of the instrument (Best, 1981). However, no matter how carefully constructed and worded, there is still the chance that the respondent will not interpret a question as it was intended by the examiner. This effect can be minimized through consultation with both professionals and non-professionals. This questionnaire was presented to several individuals for interpretation before the final instrument was constructed. Revisions were made accordingly, and are addressed in more detail in Chapter Three. Since the decision was made to distribute only one instrument, as opposed to two administrations of the same instrument, reliability was not measured. This decision was made in an attempt to minimize the amount of time and effort required by the participant.

## CHAPTER TWO

### Review of the Literature

There is currently a paucity of information available which addresses the needs of the families of dysphasic patients, even though the existence of family needs was recognized in literature more than three decades ago by Turnblom and Myers (1952) and Biorn-Hansen (1957). Only relatively recently do we find attempts made to define those needs. There appeared to be an increase in the amount of available literature on the topic in the 1970's. But, even with the gradual increase in interest on the topic in the past thirty years, there is a minimal amount of literature available when compared to the amount of time since the recognition of the problem (Newhoff and Davis, 1978).

### Need for Counseling

#### Effect of Trauma on the Patient

Dysphasia is associated with injury or trauma to one or more of the brain's communication centers. The etiology, site of lesion, and degree of injury are prime determinants of the severity of the

dysphasia. Although the primary effect of dysphasia is generally considered to be linguistic, any breakdown in receptive and/or expressive communication affects virtually every parameter of an individual's life. If the lesion is localized in the receptive area of the brain, the individual's ability to process what is heard is impaired. If the site of the lesion is centered in the expressive area, the ability to formulate and deliver messages to others is impaired. These impairments can be experienced separately, or jointly, and in varying degrees. But, whatever the type or extent, language, which has probably been a person's primary means of relating to the world, has been altered. This alteration can result in social, physical, emotional, and economic problems for the individual and family.

A symptom frequently observed in people having experienced brain injury is some degree of physical paralysis (Boone, 1965). Because of these new, and usually unexpected experiences, dysphasic patients and their families must make what can be very sudden alterations in the functions and responsibilities of individual family members. These changes can be vocational, personal, and social.

Vocational difficulties seemed to be experienced by the patient and family if the patient was employed. A study done by Biorn-Hansen (1957) suggested that

dysphasia patients often experienced problems accepting what were considered to be more realistic estimates of their work limitations and financial status. Cerebral injury of any degree generally requires hospitalization, which can put an unexpected financial and emotional burden on the family.

Any type of previously mentioned problems, singly or in combination, can result in new and unfamiliar responses on the part of the patient. Biorn-Hansen (1957) and Haynes and Greenburg (1976) observed marked depression post-onset which is thought to result from a loss of self-esteem, as well as the patient's unwillingness to accept the physical and cognitive limitations imposed by the trauma. Dramatic alterations have occurred in a patient's life virtually overnight. Unable to work or otherwise constructively use this time, it is reasonable that the patient might become preoccupied with changes in specific abilities, physical conditions and interpersonal relationships. This type of chronic depression can be detrimental to the patient's recovery of both physical prowess and communication skills. Anxiety was also an observed response which closely paralleled the depression (Biorn-Hansen, 1957).

Often, increased dependency becomes a factor in a long-term illness such as a stroke. Biorn-Hansen



(1957) found that any such long-term illness tends to intensify the patient's pre-morbid personality. Therefore, if a patient was of a dependent nature, however subtle, prior to the trauma, that dependency becomes magnified.

Another emotional response which has been associated with brain injury such as a stroke is emotional lability. This reaction has been considered to be one of the more commonly observed changes in dysphasic patients (Boone, 1965) and refers to the fact that a person has a lower threshold of emotional reaction. It requires less emotional stimulation to generate tears or laughter in the patient.

Haynes and Greenburg (1976) also suggest that guilt is another emotional reaction experienced by the dysphasic patient. This emotion appears to have two primary catalysts. These involve (a) relinquishing a major role in the family unit as a result of the trauma, and (b) concern about the financial and social alterations that will have to occur in order to compensate for the patient's condition.

There are other behavioral factors that frequently accompany brain injury and dysphasia, either singly or in combination: egocentricity,

reduced response latency, perseveration, distractibility, concretism, and fatigue. All of these factors, while occurring in the patient, can affect the family.

The dysphasic patient often becomes more egocentric after the trauma. Haynes and Greenburg (1976) speculated that this could be related in some way to the patient's loss of speech, which they consider to be an "ego-gratifying act" (pg. 18). By impairing the patient's communication, dysphasia also impairs the socially accepted channel for egocentric behavior - speech. Therefore, this egocentric behavior searches for other outlets and, as is the case with other emotions and behaviors, may intensify after the onset of dysphasia.

An increase in the amount of time required by the patient to respond to a question may also become a factor. Reduced response latency could be the result of inefficient processing of syntactic, semantic, morphological, and phonological rules required to understand and respond appropriately to a verbal stimulus (Haynes and Greenburg, 1976).

Perseveration is another behavior that is often experienced following brain injury. Perseveration is the repetition of a verbalization or motor act after it ceases to apply to a situation. This constant repetition can be distracting and

frustrating for both the listener and the speaker, possibly even resulting in a lack of desire to communicate on the part of one or both participants. The speaker is often aware of the repetition, but may be unable to interrupt the pattern (Boone, 1965).

Dysphasia patients can also become more easily distracted after the trauma according to Haynes and Greenburg (1976). Distraction could result from perseverative behaviors or from changes in routines or environment. Also, the presence of too much stimulation can have an effect on their performance, possibly leading to compulsive behaviors (Boone, 1965) on the part of the patient in an attempt to reduce the number of environmental distractions. This factor can be disturbing to both families and patients, especially when efficiency in thought and expression is necessary.

Dysphasia can also affect an individual's ability to deal with abstract concepts. It is usually easier for a dysphasic patient to process and communicate about events that have just occurred, than events that have occurred in the more distant past, or that will occur in the future. Often dysphasic individuals find it difficult to generalize from past experiences in order to help them deal more effectively with

present solutions (E. Hutchinson, personal communication, 1983)

A final behavioral concern often seen in dysphasics is that they tire more easily. This can occur with any illness of this magnitude, but it carries particular pertinence to the rehabilitation process. Haynes and Greenburg (1976) have indicated that perhaps many of the maladaptive behaviors (e.g. perseveration, distractability) may occur with greater frequency or with greater intensity when demands are placed upon an already fatigued patient.

As a result of the changes in an individual, dysphasia may affect interpersonal relationships. Dysphasia can cause changes in patients' behavior and emotional reactions, thus altering the way in which they relate to others. Biorn-Hansen (1957) reported a sensitivity to joking, aggressiveness, and hostility in some of the subjects in her study. Withdrawal also seemed to be a frequent reaction by dysphasic subjects. Studies conducted by Biorn-Hansen (1957), Turnblom and Myers (1952) and Malone (1969) suggest that such changes in the attitudes and behaviors of an individual often had serious effects on interpersonal relationships. Deterioration in these relationships could impact on aspects of a patient's life other than interpersonal interaction.

An individual's interactions with others can affect attitudes towards oneself, and thus impede recovery.

With such changes in a person's physical, emotional, and communicative abilities, concomitant changes in the roles of family members is often required. Eisenson (1973) referred to changes in the family economic roles. For example, the individual who suffers a stroke may have to relinquish a particular role once played in the family such as "breadwinner" or "home-maker", at least temporarily. Then, the issue could be further complicated by the person who assumes that role either being reluctant to accept that responsibility in the first place, or being unwilling to relinquish it after the patient recovers. Biorn-Hansen (1957) found that these role changes could potentially result in marital conflicts.

#### Effect of Trauma on the Family

It is very difficult to separate the emotional effects of dysphasia on the patient and the effects on the family. This is because generally what affects one member of a family unit affects all members (McCormick and Williams, 1976). As alluded to earlier, major changes occur in the family unit (Florance, 1979). Biorn-Hansen (1957) and Malone

(1969) discuss possible problems that could occur in the family unit as a result of changes in authority.

Marital problems could result following the onset of dysphasia. These could be caused by alterations in the patient's personality, by alterations in the structure of the family unit, or by sexual difficulties that may, but do not necessarily, accompany dysphasia (Biorn-Hansen, 1957).

Concerns regarding children can frequently arise. Biorn-Hansen (1957) found that her patients felt that they were unable to "fully" participate with their children, or they became irritated by the confusion sometimes associated with children. Also, children were sometimes unable to understand the changes in their parent, and often felt abandoned (Malone, 1969).

Economics is yet another family concern. The patient may have been the provider prior to the onset of dysphasia, and can no longer continue in that capacity. Therefore, according to Turnblom and Myers (1952) and Malone (1969) there is often a decreased income, complicated by increased medical expenses.

McCormick and Williams (1976) suggest that families experience certain anxieties "peculiar to stroke" (pg. 315). McCormick and Williams (1976), Linebaugh and Young-Charles (1978), and Turnblom and

Myers (1952) all suggest that the anxiety experienced by families is usually greater than is readily visible to an outsider.

Numerous authors have attempted to label emotional reactions frequently experienced by families of dysphasic patients. Biorn-Hansen (1957) and Malone (1969) describe overprotection of the patient, as well as rejection, possibly in the form of subtle belittling, as frequent family reactions. Malone (1969) also noted irritability and feelings of guilt in family members taking part in his study. Other feelings suggested by Linebaugh and Young-Charles (1978) included helplessness, hostility, pity, and shame.

Some family members also indicated to Linebaugh and Young-Charles (1978) changes which occurred in their social lives. They reported that friends seemed to be "fading away", possibly as a result of significant personality changes which had occurred in the patient, or possibly because the family members felt they should devote the majority of their time to the patient and forgo social activities.

Dysphasia carries with it many misconceptions about a patient's abilities and inabilities, simply because of the more visible signs associated with it (e.g. impaired communication and, possibly, impaired physical abilities). In a study done by

Helmick, Watamori, and Palmer (1976), the results suggested that the spouses of dysphasic patients did not understand the extent of the impairment of the patient's language. Some felt that the damage was more extensive, while others felt that it was not as severely impaired as was actually the case. This resulted in the very frustrating problem of having unrealistic expectations about outcome, and thus burdening the patient with unrealistic demands. Boone (1969) found that many spouses assumed that the patients were "helpless", when in reality they were not, and could have benefited from being given more opportunities to use their existing skills.

Finally, concerning misconceptions, impairment of expressive language often results in the immediate misconception that an individual is "mentally deficient". Haynes and Greenburg (1976) point out that while an initial depression in mental functioning is possible, it is usually only temporary.

All of these misconceptions are very frustrating to both the patients and their families. Because these misconceptions often result in the fostering of unnecessary dependence on the part of the patient, or simply in anger and frustration on everyone's part, they can be destructive to recovery and interpersonal relationships.



All of these traumatic changes in the patients and their families usually result in anger, frustration, and confusion. These are emotions that must be dealt with constructively if the greatest possible therapeutic gains are to be made. Various sources have attempted to emphasize that a stimulating and understanding environment is vital to the recovery of the patient (Wepman, 1969, McCormick and Williams, 1976, Czvik, 1977 and Florance, 1979).

#### Family's Role in Rehabilitation

The majority of recovering dysphasic patients return to their homes after being discharged from the hospital according to Eisenson (1973) and Wepman (1969). Therefore, family members should be considered as integral parts of the patient's convalescence. In research done by McCormick and Williams (1976) and Czvik (1977), it was found that good family relationships enhance a patient's recovery. Czvik (1977) found that, although patients with Class I receptive dysphasia had a poor prognosis, moderate success was achieved when family members contributed to rehabilitation. Eisenson (1973) stated that he felt a good family attitude was a form of therapy in itself. Conversely, McCormick and Williams (1976) and Stoicheff (1960) found that

negative family relationships could handicap the rehabilitation process.

The use of a "significant other" can be beneficial in therapy. Florance (1979) found that the use of a family member for therapeutic purposes could accomplish the following goals: (a) decrease total time in therapy, (b) assist in generalization, and (c) enhance the permanence of the desired behavioral change. Ritter (1976) devised a specific therapy approach to address the problem of patients who seemed to "dichotomize what he learns with the speech and language clinician and what he does with the family" (pg. 200). Studies done by Helmick, Watamori, and Palmer (1976) and Scheull, Jenkins, and Jimenez-Pabon (1964) support the fact that the verbal behavior of spouses of dysphasia patients can either reinforce or hinder language recovery.

As these studies suggest, family members are an integral part of the rehabilitation team. The fact that a sudden and dramatic change has occurred in their lives could affect their ability to assist the patient.

#### Counseling

In a study done by Linebaugh and Young-Charles (1978) it was found that subjects felt that counseling and family guidance should be offered to

all families of dysphasic patients. Helmick, Watamori, and Palmer (1976) suggest that speech pathologists should serve as counselors. Schuell, Jenkins, and Jimenez-Pabon (1964) indicated that the therapist's primary objective in counseling should be to "help the family to understand and accept the limitations imposed by severe aphasia" (pg. 375). Malone and Malone (1977) stated in a discussion of family guidance, that they felt that speech pathologists were "the best qualified to counsel about aphasia, because we have a better understanding of the problem than do other disciplines" (pg. 159). Others suggest that counseling should be offered by other disciplines singly, or as a part of a team. Brookshire (1978) suggested that counseling be conducted by a speech pathologist or other qualified professional, while the American Heart Association (1969) suggested that a doctor, clergyman, or psychologist direct it.

The primary objectives of therapy should include helping the family understand and accept the changes which have occurred in the patient. Turnblom and Myers (1952) state that counseling should facilitate the family's emotional adjustment. They suggest that there are six counseling goals:

- 1) Ventilation
- 2) Reassurance
- 3) Education/Orientation
- 4) Alleviation of Guilt
- 5) Sharing of Responsibility
- 6) Assistance in the Adoption of a Constructive Outlook

Scheull, Jenkins, and Jimenez-Pabon (1964) define three components of beneficial counseling: (a) the acceptance of the patient's limitations, (b) education of the family to the patient's capabilities, and (c) "achieving and maintaining communication" (pg. 376).

The specific topics to be addressed in counseling vary. Most sources seem to suggest that the topics should be fairly comprehensive rather than being limited to communication. Since dysphasia affects all areas of a family's existence, counseling should at least touch upon all areas of family life. McCormick and Williams (1976) discuss topics in their counseling program which were selected by participants. Some of those topics included:

- 1) Cause of Stroke
- 2) Physical Management of the Patient
- 3) Medical Concerns
- 4) Psychological Factors (e.g. ego-defense mechanisms, hostility)
- 5) Death and Dying
- 6) Dietary Management
- 7) Relaxation
- 8) Sexual Impotence

This was felt to be a comprehensive list of topics which are covered by many other counseling programs examined.

Family members involved in counseling know the areas in which they need information and support, which is why the pervasive opinion is that they should be allowed to select the topics. However, in certain instances they may need guidance in understanding more fully why a particular issue is of importance.

Proper family guidance and counseling creates an environment which is more conducive to the recovery of the patient. McCormick and Williams (1976) suggest that both families and patients profited from the opportunity to discuss fears, hostilities and needs. Florance (1979) agrees that counseling may prevent maladaptive behaviors caused by the development of faulty interaction patterns resulting from fears, anxiety, and misconceptions. An example of this might be a family member not allowing the dysphasic patient the opportunity to use his or her abilities fully, thus fostering unnecessary dependence, frustration, and hostility on the part of the patient. Biorn-Hansen (1957) found that when counseling was begun early in the rehabilitative process, marital conflicts seemed to be reduced.

As mentioned earlier, the literature suggests that by educating and using family members as therapists, generalization of therapy can be enhanced. Stoicheff (1960) suggests that only with counseling

programs for families can maximum language recovery be reached. Family guidance can give support and direction for families suddenly faced with new situations, and it can increase their empathic understanding of the patient. Family counseling can help families through difficult emotional adjustments that are presented throughout the patient's recovery process (Turnblom and Myers, 1952).

### Conclusions

Family guidance should optimally achieve a careful balance in its concern for the patient and for the family. Special care should be given in counseling to emphasize the importance of the family's role in the patient's recovery. The family must not be made to feel that the patient's physical, emotional, and communicative rehabilitation depends entirely upon them (Boone, 1965). The responsibility lies in a successful team effort between the patient, the family and the health care team. Each has a vital responsibility in the patient's recovery, and less than full cooperation from any one link can cause the serious impairment of the entire process.

### Summary

All of this information supports the fact that the families of dysphasic patients are very necessary components of the rehabilitation team. But, "strokes befall families rather than discrete individuals" (McCormick and Williams, 1976, pg. 315) and therefore families often need assistance in adjusting to the changes in their lives. Perhaps, once they have a better understanding of dysphasia and how it effects their lives, families can reach their maximum potential as active members in both the patient's and their own rehabilitation process.

## CHAPTER THREE

### Methods

#### Background Information on Questionnaire

The method of data collection used was an anonymous survey. The purpose of the survey was to determine the attitudes of dysphasic patients' families regarding speech therapy and family counseling. All the respondents to the survey had been at Rex Hospital in Raleigh, North Carolina.

Rex Hospital is a private, non-profit, acute-care hospital which was founded in 1894. The patients of Rex Hospital are transient in nature, staying in the hospital only as long as direct medical attention is necessary. Once it is judged appropriate by the personal physician, the patient is released and generally returns home or to an extended-care facility.

Speech therapy services in the hospital were established in 1982. There is presently one full-time speech pathologist on staff at Rex Hospital. Anyone suspected of being dysphasic is referred by the attending physician for extensive testing to be carried out by the speech therapist.



### Subjects

The subjects selected to participate in this survey were family members of all individuals diagnosed as dysphasic from February, 1981 to April, 1983. The specific family members who received the survey were the individuals listed as "next of kin" in the patient's admitting records. Once this group was selected, the single condition for qualification was that the former patient was not deceased, to spare the families any additional emotional pain.

Surveys were sent not only to families of patients who received speech therapy services at Rex Hospital, but they were also sent to people who received therapy prior to the implementation of the hospital's self-contained program. This was a decision made jointly on the part of the hospital and the researcher. The hospital wished to be able to compare reactions of participants before and after the implementation of their program, in order to make comparisons between the two different delivery systems.

### Development of the Instrument

The first phase of the questionnaire development was to determine, in very specific terms, the problem to be analyzed. Once a specific aspect of dysphasia therapy was finalized (e.g. family counseling), the

next step was to formulate specific issues pertaining to the chosen topic (e.g. whether family guidance therapy was necessary, areas that were of concern to families, method of delivery, and who should conduct the therapy.

A major goal of the hospital was to gain information about attitudes concerning other aspects of the patient's stay. Section I of the questionnaire, "Overall Satisfaction with Hospital Services", was developed to meet this objective. Questions were also included that related directly to speech therapy services, but that did not directly pertain to issues addressed in this presentation. These included questions concerning prognosis, the reason therapy was discontinued, and overall satisfaction with the services.

Once the specific issues were determined, research was done for the purpose of developing a more efficient and reliable instrument. In other words, questions were required that would elicit maximum reliability of response, with a minimum of effort on the part of the participant.

Initially questionnaires on topics completely unrelated to the field of speech pathology were examined. This was done in an attempt to become familiar with different survey formats. Then questionnaires pertaining specifically to the topic

of dysphasia were examined. The motivating rationale behind this decision was to begin the actual process of developing individual questions. Observations were made concerning the phrasing and terminology of each question. At this point, a preliminary set of questions were prepared (see Appendix A).

The initial questions were presented to two professionals in the area of survey development in order to discover possible weaknesses in the wording or design of the questionnaire. Revisions were made with the intent of making the questionnaire as easy as possible for the participants to understand and complete (see Appendix B).

In the original instrument, section I was entitled "Preliminary Information". The rationale for changing the position of this set of questions from the opening to the closing position of the questionnaire was strategic. Frequently, possible participants are put on the defensive when initial questioning involves their personal lives (R.E. Reiman, personal communication, March 1983). Therefore it was felt that the items appearing in the first part of the questionnaire should be of a clinical, rather than personal nature.

After the decision was made to begin the questionnaire with the section entitled "Overall Satisfaction with Hospital Services" the original

response method was analyzed. The decision was made to modify the numerical scale found in the original, to a descriptive scale. The rationale for changing this to a more descriptive scale involved two considerations. The first element was examiner dissatisfaction with the ambiguity of a numerical scale in that numbers left the person completing the questionnaire to assign subjective values to each. The second reason was that there seems to be an overwhelming tendency on the part of the participants to respond using the "middle" number (G. Bolick, personal communication, March, 1983). For these reasons, it was felt that a more accurate description would be obtained using a scale that did not involve a numerical rating system.

Next, question number two in the "Overall Satisfaction with Hospital Services" section was changed from a "fill-in-the-blank" format to a more objective system where the participant had only to check the appropriate response. This was done in order to reduce the complexity of response required by the participant when responding to that particular question. Another reason was that, when analyzing the data, the objective responses were more accurately categorized, and thus summarized in terms of percentages.

The next consideration involved the simplification of instructions given to the participant. The wording of instructions was modified in order to reduce confusion in completing the next step of the survey.

#### Cover Letter

The cover letter was considered to be crucial to the success of the survey. Every aspect, from the actual presentation of the letter to the terminology used, was examined very closely.

The decision was made to print the cover letter on hospital stationery for two reasons. The first was that the survey was being done as a part of the Quality Assurance Surveys being administered by the hospital. The second reason involved the legitimacy of the questionnaire itself. An official presentation by the hospital seemed to provide additional professionalism to the survey, and thus alleviate doubts as to the questionnaire's origin.

The composition of the introduction included several basic components. The first aspect was an expression of genuine interest in the participants as individuals. Closely related to this was a statement regarding the desire on the part of the hospital to improve services to all patients and their families. Finally, an attempt was made to impress upon each participant the importance of the survey and the need

for its completion. In this way it was hoped that each participant would feel an obligation to complete and return their survey, thus increasing the actual return. It was also stated in the introductory letter that someone from the hospital would be contacting the family shortly after their receipt of the survey to answer questions or assist them in any manner. This was also seen as additional encouragement for response. The cover letter appears in Appendix B.

#### Organization of the Study

Increasing return was the major consideration in the organization of the questionnaire. The primary factor was the length of the survey. Every effort was made to keep the length of the actual instrument to a minimum to reduce any anxiety and fatigue the participant might experience.

The decision was also made to position the more important questions concerning actual speech therapy and family counseling in a medial position with regard to other questions. This was done taking two factors into consideration: warm-up time, and the element of fatigue. In this manner, allowances were made for a possible minimum of effort, during the initial and final stages of response, on the part of the participant. This was also a secondary reason

that "Personal Information" was located at the end of the survey. Response to personal questions requires a minimum of decision-making effort, therefore reducing fatigue.

The survey was divided into four distinct sections: Overall Satisfaction with Hospital Services, Speech Therapy Services, Family Counseling, and Personal Information. These sections were also divided, not only by title, but by horizontal lines between each section. The motivating rationale behind this decision was an attempt to reduce monotony associated with the completion of the questionnaire. At the end of each section space was provided for the participants to make additional comments.

### Visual Presentation

#### Graphic design

The aesthetic, as well as the functional design, was taken into consideration when determining the actual presentation of the questionnaire. This was done in order to make the completion of the questionnaire as pleasant an experience as possible.

The actual physical dimensions of the instrument were of importance. It was felt that the size should meet certain requirements, the first of which involved fitting the questions into the amount of space chosen. This decision also involved another

factor - the size of the print to be used. Additionally, the examiner did not want the length of the questionnaire to appear overwhelming to the potential respondent. Therefore, to maximize return, the number of sheets of paper contained in the initial envelope to be opened by the participant should be kept to a minimum.

With the previously mentioned examiner-imposed requirements in mind, the decision was made to use a single sheet of paper with the dimensions of eleven inches in length and eight and one-half inches in height. By using paper of these dimensions, the paper could be folded in half, producing four separate and distinct surfaces, each of a standard, eight and one-half by five and one-half inch size. In this manner, the requirements for maximum usable space, with a minimum amount of paper, were met.

As mentioned previously, the size and type of print were also a consideration. The records indicated that the majority of participants would be elderly. It was felt that the print used in the questionnaire must be easily legible, and that it would allow the entire survey to be printed within the previously specified dimensions. IBM's Manifold type was chosen.

The color of the paper to be used when printing the final form was another area requiring attention.



The decision to choose beige, as opposed to white, was made for several reasons. Beige seems to radiate warmth, without forfeiting the appearance of professionalism. Also, the tendency to misplace a survey on beige paper, as a result of putting it with other correspondence, on primarily white paper, would be reduced simply because of the visibility factor.

#### Distribution and Return

After the finalized copy of the instrument was approved by the hospital, distribution procedures began. The hospital took responsibility for the entire distribution process as well as for the actual return of the questionnaire. This was done in order to assure the mandatory confidentiality of each patient and their family.

Rex Hospital distributed a total of fifty questionnaires. These questionnaires were mailed in Rex Hospital envelopes, with a stamped, self-addressed envelope enclosed to allow for as prompt and effortless a return as possible.

As indicated in the introductory letter, the questionnaire was followed two to three days later by a phone call to every recipient from an official Rex Hospital representative. The purpose of this phone call was to answer any questions the

participants might have had regarding the questionnaire. The nature of the questions was not limited in that they could address anything from the purpose of the questionnaire, to questions regarding any individual items about which the participants may have had a concern. This telephone conversation also served to encourage prompt return of the questionnaire or as an opportunity to offer assistance in its completion. A total of seven questionnaires were completed over the telephone, for reasons ranging from loss of the instrument to poor eye-sight on the part of the participant, which interfered with their ability to read and complete the questionnaire.

The time allowed for the return of the questionnaire was three weeks. This time period was chosen for two reasons. The first factor was that to allow any greater length of time would be adding the additional risk that the questionnaire would be lost. To allow any less time could possibly make the participants feel rushed, and therefore make them less inclined to even begin the task of responding. No questionnaires were received after the three week deadline.

## CHAPTER FOUR

### Results

#### Analysis

Fifty questionnaires were distributed to the families of dysphasic patients. Twenty-six questionnaires were returned for a total of 52%. Results were presented in the form of a percentage for two reasons. The primary reason was that a percentage is more easily interpreted by a majority of individuals, regardless of their educational background. Also, percentages provide for easier replication and comparison for future studies.

Initially questions were analyzed individually by dividing them into objective and subjective question categories. Objective questions were defined as those which provide for "marking a yes or no, a short response, or checking an item from a list of suggested responses" (Best, 1981, pg. 168). An example of an objective question would be "Was family counseling offered?" (number 12) or, "What was the primary method of counseling?" (number 15). Subjective questions were considered to be those

questions which allowed for an original response in the respondents' own words. An example of a subjective question would be number ten, "In your opinion, how could speech therapy services be improved?"

In the case of the subjective questions, each response was analyzed by two parties. The examiner and an "impartial party" analyzed each question separately, and then together determined the appropriate category for each response. This was done in order to be able to report the results in terms of percentages, as mentioned previously. To illustrate the point, question number nine, "Why was therapy discontinued?" was considered by the examiner to be subjective. Therefore it was subjected to the two-party analysis mentioned previously. As a result of this analysis, it was determined that each response fell into one of six major categories, which will be discussed in more depth later. This division allowed the results to be reported in terms of percentages.

#### Outcome

The results of the sections entitled "Speech Therapy Services" and "Family Counseling" are included in this section. The results of the remaining sections can be found in Appendix C.

### Speech Therapy Services

Of the 26 individuals responding to this questionnaire, all stated that the patient was offered some type of speech therapy, with 97% actually receiving services. Eighty-six percent of respondents seemed to feel that the patient's communication prognosis was clearly explained to the family by the therapist. When asked whether, in their opinions, the prognosis that was explained to them was achieved, 70% said that they felt that it was, while only 30% were dissatisfied.

Speech therapy appeared to be a relatively short process in that the majority of individuals (76%) reported that services lasted less than six months. Considerably fewer people received services for more than six months, with the number decreasing dramatically as the length of time increased (see Table 1).

There were several reported reasons that the services were discontinued, but three reasons constituted 80% of the total: therapy was not accessible after the patient was discharged from the hospital (30%), the patient was judged to have achieved maximum benefits from the program (27%), or the patient's physical condition deteriorated (23%). Other reasons given were that therapy had not been

Table 1

Duration of Services

|                         |     |
|-------------------------|-----|
| Less Than 6 Months ...  | 76% |
| 6-12 Months ...         | 14% |
| 13-18 Months ...        | 0%  |
| 19-24 Months ...        | 5%  |
| More Than 24 Months ... | 5%  |

discontinued as of the completion of the questionnaire, monetary concerns, and deterioration of the patient's emotional condition. Upon discharge from the hospital, patients generally went to either some type of extended care facility, or to their homes. Therefore, if the patients were not living where the services were provided, it was frequently difficult, if not impossible for them to seek such services independently.

A large number of patients were judged to have reached their maximum communication goals. Most frequently this judgement seemed to have come from a speech pathologist. However, there were several instances where the persons making the decision were unidentified.

The next most frequently occurring reason given for the discontinuation of services was deterioration of the patient's physical condition (see Table 2). Responses falling into this category were those where the patient expired, or where medical problems were of greater concern (e.g. terminal cancer).

The majority of people stated that they were quite satisfied with the overall speech therapy services, and felt that they were "adequate" or "more than adequate" (95%). Only five percent indicated that they felt services were "less than adequate." Most respondents (78%) suggested that there was no

Table 2

Reasons for Discontinuation of Services

|                          |     |
|--------------------------|-----|
| Therapy Inaccessible     | 30% |
| Reached Maximum Benefits | 27% |
| Physical Deterioration   | 23% |
| Therapy Not Discontinued | 9%  |
| Monetary                 | 5%  |
| Emotional Deterioration  | 5%  |



improvement needed in the services. Of the 22% making suggestions for improvement, the primary response seemed to be that services could be improved by increasing the number of sessions (12%). Other suggestions involved placing greater emphasis on articulation (5%), and having more experienced clinicians (5%).

In summary, analysis of this section of the questionnaire suggested that a majority of individuals who were offered speech therapy services received them, although for less than six months. Most people were satisfied with the communication prognosis, both in the way that it was explained to them, and in its achievement. There were several reasons for the discontinuation of therapy, but most frequently they involved the achievement of the prognosis, inaccessibility of services, and the deterioration of the patient's condition. Finally, the majority of respondents reported that they were satisfied with the services received and did not feel any improvement in the services or their delivery was necessary.

#### Family Counseling

Family counseling was offered to and received by only 48% of the respondents, with 52% neither being offered or receiving the service. All those individuals offered the service reported that they

took advantage of it. There did not seem to be any significant difference between the ages of the patients whose families were offered counseling (47-82 years) and those who were not offered counseling (48-75 years). There also does not appear to be any parallels between those who did or did not receive counseling and the date of their hospitalization.

Service delivery was conducted primarily by the speech pathologist (in 50% of reported cases), and by the social worker (in 25% of reported cases). Frequently there appeared to be a team effort involving two or more disciplines (63%). Counseling was also offered in some form by physicians (8%), physical therapists (8%), and the health department (8%). The greatest number of people (29%) reported that they felt that ideally, the speech pathologist should conduct the counseling sessions. Other suggestions included the social worker, psychologist, and a "trained counselor." Only 14% of the respondents felt that some sort of "team effort" could achieve maximum results.

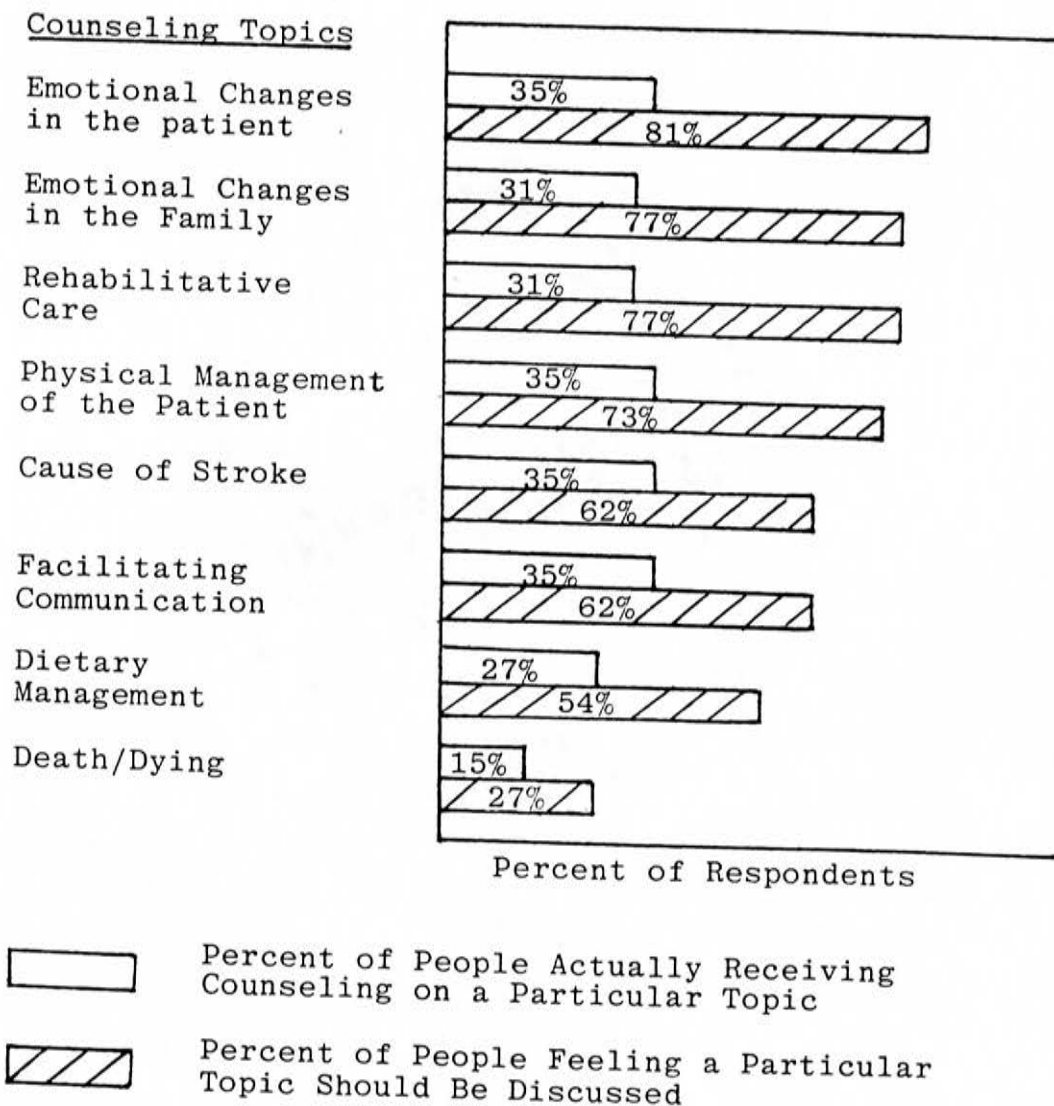
Counseling seemed to take place in an individual setting (reported by 100% of those receiving counseling). However, individual therapy was combined with group therapy in approximately 9% of the cases, and with reading material in 36% of the cases.

There appeared to be eight primary areas covered in the counseling received by the respondents. The most frequently occurring topics seemed to be "handling the emotional aspects of changes occurring in the patient" (35%), "physical management of the patient" (35%), "cause of the stroke" (35%), and "ways to facilitate communication" (35%). The next most frequently discussed topics were: "handling emotional aspects of changes within the family unit" and "rehabilitative care" available to the patient and family. The two topics apparently discussed least were dietary management of the patient, and "death and dying."

Ideally, people seemed to feel that the most important topic to be discussed should be the "emotional aspects of changes in the patient" (81% of respondents felt this to be a necessary topic). Hierarchically, the other topics to be considered were as follow: "emotional aspects of changes in the family unit, rehabilitative care available, physical management of the patient, causes of stroke, ways to facilitate communication, dietary management," and finally, "death and dying." See Figure 1 for comparisons.

Figure 1

Actual Versus Ideal Emphasis  
of Counseling



The largest number of individuals responding to this questionnaire felt that family counseling should continue for an indefinite period of time (42%). Others felt that counseling was necessary only as long as the patient was hospitalized (32%), and still others felt that counseling would be beneficial for the duration of speech therapy services (27%).

#### Summary

Analysis of the questionnaire indicated that family counseling was received by everyone to whom it was offered. There did not appear to be any correlation between those receiving or not receiving services and the age or date of the injury. Usually counseling was conducted by a team, but counseling by a speech therapist or a social worker was considered by the respondents to be most effective. Counseling usually consisted of individual sessions with supplemental reading material, and was felt to be more effective if continued indefinitely. Also, areas of primary interest for discussion purposes seemed to involve "emotional changes in the patient" while "death and dying" seemed to have been of least interest.

## CHAPTER FIVE

### Conclusion

#### Summary of Results

##### Speech Therapy

The families involved in this survey reported that a majority of patients received some type of speech therapy, and those services usually lasted less than six months. In addition, the family members felt that the prognosis was clearly explained to them and appeared to generally be satisfied with the outcome of therapy in relation to the prognosis.

##### Family Counseling

Families appeared to feel a need to discuss their new situation and to explore ways in which to deal with it because everyone who was offered counseling accepted. Most frequently counseling took place in some type of individual arrangement, conducted by a speech pathologist or social worker. Although there appeared to be several topics involved in family counseling, the primary areas seemed to be the cause of stroke, the physical management of the patient, emotional aspects of changes in the patient, and ways

in which to facilitate communication. Death and dying were areas of much lesser emphasis.

When families were asked to express their thoughts regarding the topics they felt would be most beneficial to families of dysphasia patients, their list was somewhat different than what was actually discussed in counseling. The families seemed to feel that the most important area would be the discussion of the emotional changes in the patient. The next highest areas of interest included learning about rehabilitative care available to the patient, the emotional aspects of changes in the family, and physical management of the patient. Ways in which to facilitate communication fell relatively low on the list of priorities, with death and dying being the lowest. In addition, families suggested that counseling should be led by a speech pathologist, and that it should continue for an indefinite period of time.

#### Discussion

The conclusions of this questionnaire supported findings of other researchers - families seemed to feel that family counseling was beneficial. It is uncertain as to whether the families related the usefulness of counseling to the affect the family had on the patient's recovery or whether it was simply to

the direct benefits received by the family (e.g. understanding of the problem, coping skills, support services, etc.).

The emphasis in counseling may have been affected by the individual conducting the sessions in that a majority of sessions seemed to be conducted by a speech therapist. Within the outline of the sessions reported, communication appeared to be a primary area of discussion even though the participants did not consider it to be a major focus of their concern. This suggests that (a) either participants were not fully aware of the impact of a communication impairment or (b) that they were aware, but more concerned with more immediate, threatening problems (e.g. physical management of emotional stability. A possible implication is that family guidance can take place apart from communication therapy. Although a contradicting preference was that families seemed to prefer that counseling be conducted by a speech pathologist. Families did seem to be the most concerned with understanding the immediate needs of the stroke patient as opposed to the needs of the dysphasic individual. This may be a natural response to such a crisis in that communication might not be considered, at first glance, to have a direct effect on a person's physical or emotional well-being. However, the fact that death and dying were felt to



be of such relatively minor significance was considered to be noteworthy. It appears that the idea of death might be a very realistic consideration for a family after one of its members has suffered a life-threatening event such as a stroke or some other type of injury to the brain. But, according to the results of the survey, this was not an area of major concern. Perhaps this was due to the family's reluctance to consider the death of a loved-one, or perhaps it was because they felt they did not need any support when dealing with that particular issue.

One of the possible implications of the discrepancy between what people feel a need to discuss, and what is actually discussed is that professionals could be choosing the topics. That practice could have both positive and negative consequences. On the positive side, families may not fully realize the importance of some aspects of both the emotional and physical rehabilitation of the patient, and how these things may directly or indirectly affect the family. Therefore, it may be beneficial to have a trained professional to guide families in such a counseling program. However, if this guidance does not take the interests of the families into account, many needs may go unmet. So, perhaps the implications may be to find a balance of professional and family direction.

These findings imply that family needs may best be met by some sort of a "team" approach involving possible coordination by a speech pathologist. Other team members might include a social worker, nurse, psychologist, and/or occupational therapist as necessary.

#### Suggestions for Further Research

There still remain many areas of this issue to be explored. This was a small descriptive study conducted in a single hospital. Therefore its results may not be generalizable to other populations. Further research might involve replication of this type of survey with a larger, unbiased population. This questionnaire was an instrument to measure subjective feelings of families. It attempted to determine whether families felt that counseling was beneficial in helping them deal with a major change in their structure.

Further research might attempt to determine, in more objective terms, whether counseling actually affected family attitudes. One possible way in which this might be approached would be some type of attitude scale, first being administered prior to the implementation of counseling, and then at several other points during the counseling process. In this

way, some type of measure might be made of actual changes in family attitudes regarding brain injury and dysphasia.

This instrument was designed to answer specific questions concerning family guidance. But, in doing so it brought about other, equally important questions. Because of the relatively minimal amount of research done on this topic, it seems that there are many more questions requiring answers if we are to more completely understand the dynamics involved in brain injury, dysphasia, patients, and families.

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APPENDIX A

Preliminary Instrument

## I. PRELIMINARY INFORMATION

1. Is your spouse male or female? (Please circle)
2. Date of Stroke \_\_\_\_\_
3. Age of Spouse at the Time of Stroke \_\_\_\_\_
4. Spouse's educational level (years of school completed) \_\_\_\_\_
5. Spouse's Occupation \_\_\_\_\_
6. Average Family Income per Year (Check One)
- \_\_\_ Below \$5000.    \_\_\_ \$5000.-14,999.
- \_\_\_ \$15,000-29,999.    \_\_\_ Above \$30,000.
7. Type of Stroke or Disability (If Unable to Name, Please Describe)

## II. OVERALL SATISFACTION WITH HOSPITAL SERVICES

- |  | less<br>than<br>adequate | adequate | more<br>than<br>adequate | not<br>applicable |
|--|--------------------------|----------|--------------------------|-------------------|
| 8. Physical Therapy                                | 1                        | 2        | 3                        | 4                 |
| 9. Occupational Therapy                            | 1                        | 2        | 3                        | 4                 |
| 10. Dietary  | 1                        | 2        | 3                        | 4                 |
| 11. Nursing Care                                   | 1                        | 2        | 3                        | 4                 |
| 12. Physician's Explanation of Patient's Condition | 1                        | 2        | 3                        | 4                 |
13. Approximately how many times did you visit the hospital during the patient's stay? \_\_\_\_\_
14. Additional Comments About Any Hospital Services:



## III. SPEECH THERAPY SERVICES

15. Was Speech Therapy offered?  YES  NO
16. Was Speech Therapy received?  YES  NO
17. Was patient's expected recovery explained in terms understandable to family members?  
 YES  NO
18. In your opinion, was expected recovery achieved?  
 YES  NO
19. How long did Speech Therapy continue? \_\_\_\_\_
20. Why was therapy discontinued?
21. In your opinion, how could Speech Therapy be improved?
22. Rate your overall satisfaction with Speech Therapy services  
 less than adequate  adequate  more than adequate

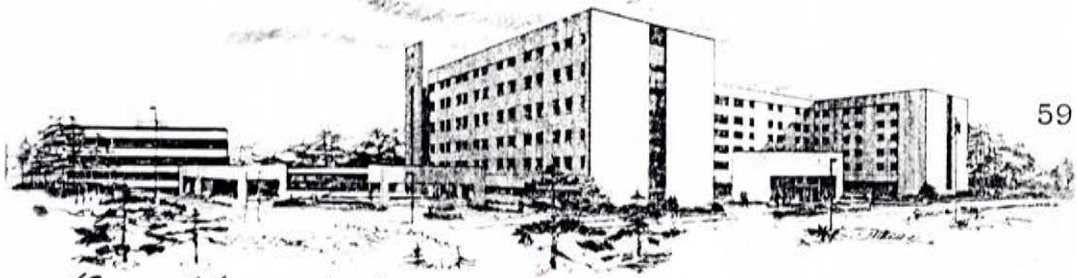
## IV. FAMILY COUNSELING

23. Was Family Counseling Offered?  YES  NO
24. Was Family Counseling Received?  YES  NO
25. Who conducted the Family Counseling program?  
 Social Worker  Speech Therapist  
 Psychologist  
 Other (please specify) \_\_\_\_\_
26. What was the primary method of counseling?  
 Individual  Group  Reading Material  
 Other

27. What areas were covered in the Family Guidance program?
- Cause of Stroke
  - Rehabilitative Care Available
  - Physical Management of the Patient
  - Handling Emotional Aspects of Changes in the Family
  - Handling Emotional Aspects of Changes in the Patient
  - Death and Dying
  - Dietary Management
  - Facilitating Communication
28. Rank your overall satisfaction with Family Counseling services
- 1            2            3            4
29. What areas do you feel should be covered in Family Counseling?
- Cause of Stroke
  - Rehabilitative Care Available
  - Physical Management of the Patient
  - Handling Emotional Aspects of Changes in the Family
  - Handling Emotional Aspects of Changes in the Patient
  - Death and Dying
  - Dietary Management
  - Facilitating Communication
30. How long do you feel Family Counseling should be offered?
- Duration of hospitalization
  - Duration of Speech Therapy
  - Indefinitely

APPENDIX B

Instrument



*Rex Hospital* 4420 Lake Boone Trail/Raleigh, North Carolina 27607

We are continually attempting to improve our services to stroke patients and their families. In order to do this we need your help. You have been chosen because of your involvement with our Speech Therapy Department. Support from families such as yours can be of great benefit to our hospital and future clients.

Enclosed you will find a survey concerning the Speech Therapy Department. We would like you to take a few moments of your time to give us your opinions regarding our program. You can do this by completing this brief questionnaire and returning it by May 21, 1983. For your convenience we have provided you with a stamped, self-addressed envelope for its return. Your opinions will remain strictly confidential and you will be unable to be identified.

We realize that strokes affect families, not just individuals, which is why we have sent this questionnaire to the patient's family members. The results of this survey will be used to uncover possible areas for improvement in speech and family guidance services. We want to be able to better serve you and any future clients. Your assistance is vital because the opinions of every person are important to the outcome of the survey.

Someone from the hospital will be in contact with you in two or three days to answer any questions you may have. We sincerely appreciate your time and assistance.

Thank you,

L. Ann Hodges, CLPT  
Rehabilitation Services

LAH:dby

Enclosure

## OVERALL SATISFACTION WITH HOSPITAL SERVICES

- | 1. PLEASE CHECK                                | LESS<br>THAN<br>ADEQUATE | ADEQUATE | MORE<br>THAN<br>ADEQUATE | NOT<br>APPLICABLE |
|--|--------------------------|----------|--------------------------|-------------------|
| PHYSICAL THERAPY                               | ( )                      | ( )      | ( )                      | ( )               |
| OCCUPATIONAL THERAPY                           | ( )                      | ( )      | ( )                      | ( )               |
| DIETARY  | ( )                      | ( )      | ( )                      | ( )               |
| NURSING CARE                                   | ( )                      | ( )      | ( )                      | ( )               |
| PHYSICIAN'S EXPLANATION OF PATIENT'S CONDITION | ( )                      | ( )      | ( )                      | ( )               |
2. APPROXIMATELY HOW MANY TIMES DID YOU VISIT THE HOSPITAL DURING THE PATIENT'S STAY?  
 \_\_\_\_\_ EVERY DAY \_\_\_\_\_ EVERY OTHER DAY  
 \_\_\_\_\_ TWICE A WEEK OTHER: \_\_\_\_\_
3. ADDITIONAL COMMENTS ABOUT ANY HOSPITAL SERVICES:

## SPEECH THERAPY SERVICES

4. WAS SPEECH THERAPY OFFERED? \_\_\_ YES \_\_\_ NO
5. WAS SPEECH THERAPY RECEIVED? \_\_\_ YES \_\_\_ NO  
(IF NO GO DIRECTOR TO NO. 12)
6. WAS THE PATIENT'S EXPECTED SPEECH RECOVERY (PROGNOSIS) EXPLAINED BY THERAPIST IN TERMS UNDERSTANDABLE TO FAMILY MEMBERS?  
 \_\_\_ YES \_\_\_ NO
7. IN YOUR OPINION, WAS THE EXPECTED SPEECH PROGNOSIS ACHIEVED? \_\_\_ YES \_\_\_ NO

8. HOW LONG DID SPEECH THERAPY CONTINUE?  
 \_\_\_ LESS THAN 6 MONTHS \_\_\_ 6-12 MOS.  
 \_\_\_ 13-18 MOS. \_\_\_ 19-24 MOS. \_\_\_ 25+ MOS.
9. WHY WAS THERAPY DISCONTINUED?
10. IN YOUR OPINION, HOW COULD SPEECH THERAPY SERVICES BE IMPROVED?
11. RATE YOUR OVERALL SATISFACTION WITH SPEECH THERAPY SERVICES (CHECK ONE):  
 \_\_\_ LESS THAN ADEQUATE \_\_\_ ADEQUATE  
 \_\_\_ MORE THAN ADEQUATE

## FAMILY COUNSELING

12. WAS FAMILY COUNSELING OFFERED? \_\_\_ YES \_\_\_ NO
13. WAS FAMILY COUNSELING RECEIVED? \_\_\_ YES \_\_\_ NO  
 (IF NO GO DIRECTLY TO NO. 18)
14. WHO CONDUCTED THE FAMILY COUNSELING PROGRAM?  
 \_\_\_ SOCIAL WORKER \_\_\_ SPEECH THERAPIST  
 \_\_\_ PSYCHOLOGIST OTHER: \_\_\_\_\_
15. WHAT WAS PRIMARY METHOD OF COUNSELING?  
 \_\_\_ INDIVIDUAL \_\_\_ GROUP \_\_\_ READING MATERIAL  
 OTHER: \_\_\_\_\_
16. WHAT AREAS WERE COVERED IN THE FAMILY GUIDANCE PROGRAM? (CHECK AS MANY AS APPLY)
- \_\_\_ CAUSE OF STROKE  
 \_\_\_ REHABILITATIVE CARE AVAILABLE  
 \_\_\_ PHYSICAL MANAGEMENT OF PATIENT  
 \_\_\_ HANDLING EMOTIONAL ASPECTS OF CHANGES IN FAMILY  
 \_\_\_ HANDLING EMOTIONAL ASPECTS OF CHANGES IN PATIENT  
 \_\_\_ DEATH AND DYING  
 \_\_\_ DIETARY MANAGEMENT  
 \_\_\_ FACILITATING COMMUNICATION  
 \_\_\_ OTHER (PLEASE SPECIFY: \_\_\_\_\_)

17. RATE YOUR OVERALL SATISFACTION WITH FAMILY COUNSELING SERVICES:  
 LESS THAN ADEQUATE     ADEQUATE  
 MORE THAN ADEQUATE
18. WHAT AREAS DO YOU FEEL SHOULD BE COVERED IN FAMILY COUNSELING? (CHECK AS MANY AS APPLY)
- CAUSE OF STROKE  
 REHABILITATIVE CARE AVAILABLE  
 PHYSICAL MANAGEMENT OF PATIENT  
 HANDLING EMOTIONAL ASPECTS OF CHANGES IN FAMILY  
 HANDLING EMOTIONAL ASPECTS OF CHANGES IN PATIENT  
 DEATH AND DYING  
 DIETARY MANAGEMENT  
 FACILITATING COMMUNICATION  
 OTHER (PLEASE SPECIFY): \_\_\_\_\_
19. WHO DO YOU FEEL SHOULD CONDUCT THE FAMILY GUIDANCE PROGRAM?  
 SOCIAL WORKER     SPEECH THERAPIST  
 PSYCHOLOGIST     OTHER: \_\_\_\_\_
20. HOW LONG DO YOU FEEL FAMILY COUNSELING SHOULD BE OFFERED?  
 DURATION OF HOSPITALIZATION  
 DURATION OF SPEECH THERAPY  
 INDEFINITELY

## PERSONAL INFORMATION

21. RELATION OF PERSON COMPLETING FORM TO PATIENT:  
 \_\_\_\_\_
22. IS PATIENT MALE OR FEMALE? (PLEASE CIRCLE)
23. AGE OF PATIENT AT TIME OF STROKE: \_\_\_\_\_
24. PATIENT'S EDUCATIONAL LEVEL (YEARS OF SCHOOL COMPLETED):  
 LESS THAN 7     7-9     10-12     13-16  
 MORE THAN 16 YEARS
25. AVERAGE GROSS FAMILY INCOME PER YEAR:  
 BELOW \$5,000     \$5,000-\$14,999  
 \$15,000-\$29,999     \$30,000 OR ABOVE

26. PATIENT'S OCCUPATION: \_\_\_\_\_
27. DATE OF STROKE/DISABILITY: \_\_\_\_\_
28. TYPE OF STROKE/DISABILITY (IF UNABLE TO NAME,  
PLEASE DESCRIBE):

ADDITIONAL COMMENTS:



APPENDIX C

Results of "Overall Satisfaction With Hospital Services"  
and "Personal Information" Sections

## I. OVERALL SATISFACTION WITH HOSPITAL SERVICES

| 1. PLEASE CHECK:                               | LESS THAN ADEQUATE | ADEQUATE | MORE THAN ADEQUATE | NOT APPLICABLE |
|--|--------------------|----------|--------------------|----------------|
| PHYSICAL THERAPY                               | 0%                 | 43%      | 48%                | 9%             |
| OCCUPATIONAL THERAPY                           | 4%                 | 22%      | 17%                | 57%            |
| DIETARY  | 9%                 | 39%      | 30%                | 22%            |
| NURSING CARE                                   | 0%                 | 52%      | 39%                | 9%             |
| PHYSICIAN'S EXPLANATION OF PATIENT'S CONDITION | 13%                | 52%      | 26%                | 9%             |

## 2. APPROXIMATELY HOW MANY TIMES DID YOU VISIT THE HOSPITAL DURING THE PATIENT'S STAY?

86% EVERY DAY    14% EVERY OTHER DAY  
 0% TWICE A WEEK    OTHER: 0%

## 3. ADDITIONAL COMMENTS ABOUT ANY HOSPITAL SERVICES:

36% POSITIVE  
 8% NEGATIVE  
 4% COMBINATION OF POSITIVE AND NEGATIVE  
 52% NO RESPONSE

## V. PERSONAL INFORMATION

22. IS PATIENT MALE OR FEMALE? (PLEASE CIRCLE)  
 52% Male    48% Female

23. AGE OF PATIENT AT TIME OF STROKE:  
 47-84 years    mean= 66.75

24. PATIENT'S EDUCATIONAL LEVEL (YEARS OF SCHOOL COMPLETED):  
 5% LESS THAN 7    41% 7-9    14% 10-12  
 23% 13-16    18% MORE THAN 16 YEARS

25. AVERAGE GROSS FAMILY INCOME PER YEAR:  
20% BELOW \$5,000    25% \$5,000-\$14,999  
30% \$15,000-\$29,999    25% \$30,000 OR ABOVE

## VITA

Brenda Yates was born in Raleigh, North Carolina, on December 19, 1959. She attended elementary and junior high school in that city and graduated from Ravenscroft High School in June, 1978. The following September she entered Appalachian State University, and in June, 1982, received a Bachelor of Science degree in Speech Pathology and Audiology. The following summer she began study toward a Master's degree in the field of Speech Pathology and Audiology. This degree was awarded in 1985.

Currently she is employed at Western Carolina Center in Morganton, North Carolina as a Speech and Language Pathologist. This position involves providing communication services to mentally retarded and developmentally disabled individuals, with a special emphasis on augmentative communication.

The author is a member of the North Carolina Augmentative Communication Association and is currently the Chairperson of the Augmentative Communication Group at Western Carolina Center.

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Her parents are Fletcher and Dorothy Yates of Raleigh, North Carolina.