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THE DESIGN AND IMPLEMENTATION OF AN EDUCATIONAL PROGRAM
FOR THE FAMILIES OF APHASIC PERSONS

By

Janet L. Dige

B.A., University of Montana, 1976

Presented in partial fulfillment of the requirement

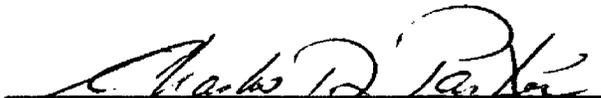
For the degree of

Master of Communication Sciences and Disorders

University of Montana

1980

Approved by:


Chairman, Board of Examiners


Dean, Graduate School

12-9-80
Date

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INTRODUCTION

Many therapists consider the total care of the aphasic important. However, there is a dearth of information regarding counseling for the aphasic individual's family. Descriptive accounts of existing treatment processes such as those by Bernstein (1978) are therefore welcomed by the working clinician. The need for such counseling services is supported by the hypothesis that both the recovering patient and his family experience the following stages: 1) denial, 2) anger, 3) depression and 4) acceptance/resolution (Sister Kenny, 1975). However, without help the family may never reach the final and most helpful stage.

The patient who has suffered a cerebral insult is often faced with an array of potentially disabling symptoms. These problems may include deficits in the areas of gross and fine motor functioning, communication skills, cognitive functioning and perceptual skills in addition to existing medical disorders. These factors may create an atmosphere of emotional stress and certainly may alter life styles and social roles for both the patient and his family.

The Mid-Maine Medical Center is an acute care hospital with 307 beds, situated in a rural community of 55,000 people. The rehabilitation unit (8 beds) serves a large number of patients who have suffered some form of cerebral insult. This unit has chosen as its goal to "add life to years instead of years to life." Aside from meeting the patient's immediate medical care needs, the patient is involved in a program designed to teach each patient to cope with his disability in such a way

that he or she can achieve the highest possible level of functioning. The retraining process calls for the services provided by a variety of professionals including the physiatrist, rehabilitation nurse, physical therapist, occupational therapist, speech pathologist, social worker and psychologist.

Mid-Maine Medical Center and other rehabilitation facilities have increasingly advocated the involvement of the patient's family in this rehabilitative effort (Turnblom and Myers, 1952; Overs and Belknap, 1967; Derman and Manaster, 1967; McCarthy, 1974; McCormick and Williams, 1976; and Dzau and Boehme, 1978). However, the family can not be expected to function in this capacity until they have been educated concerning the problems associated with a cerebral insult and what kinds of help are available.

The purpose of this project was to design and implement an educational program to enable the families of aphasic patients to take an active role in the rehabilitation process, focusing on the overall communication aspect. It was decided that a series of group counseling sessions for families be initiated. This group would not exclude or take the place of individual counseling as needed to meet more immediate needs or problems.

II. GROUP DESIGN AND IMPLEMENTATION

Survey

To aid in the development of this program a survey was sent out to 102 speech programs to gather information about current family counseling groups. Sites which were polled included regional speech and language clinics and centers located within hospitals and university settings. The survey was designed to elicit information in the areas of; 1) guest speakers participating, 2) topics covered, 3) materials available for the family members, 4) use of visual aids, 5) financial support of the group meetings and 6) means of transporting the family members to the meetings.

The response to the survey was generally enthusiastic with many clinicians expressing concern that family counseling should be a part of an aphasiology program. Notably, 60% of those polled returned the questionnaire. Of those responding, 38% indicated that their facility was conducting a counseling group for the families of their aphasic patients. A complete list of the information gained by this survey is available in Appendix A. Also included within this appendix are the percentage of affirmative responses for each suggestion within each category.

A total of 67% of the programs indicated that guest speakers participated in the family counseling group. Total suggestions for speakers was 13. The most common choices for speakers were persons likely to be a part of the rehabilitation team. These persons included a physical therapist, an occupational therapist, a nurse, a physician and a psychologist. Again the most predominate topic of selections were

consistent with those likely to be discussed by the core of rehabilitation staff members as listed above. There was a combined list of 26 topic suggestions obtained from the survey.

All programs provided materials for the family members. There were 23 suggested publications. Many of these materials are available at no cost by public health associations. Apparently the cost of the publication itself was not the primary factor in material selection. Both cost and free materials were popularly used.

Within the category of financial support, notably 39% of the programs did not charge a fee to some or all of its participants. The remaining forms of payment included private funds and varying types of third party payment.

A total of 96% of the programs polled depended upon the members use of private transportation to attend the meetings. Of these programs, 21% were able to take advantage of varying types of third party transportation to provide at least some members with a means of attending the family counseling group.

The information gained by this survey was used as a tool for creating a comprehensive yet flexible educational program for the families of aphasic individuals at Mid-Maine Medical Center. The program was based upon what this data had shown as important and based on what we felt could best meet the needs of the members of our group within a limited number of sessions.

Framework

Goals for the family group included: 1) to provide the family

with basic facts concerning common physical and psychological changes which often take place following cerebral insult, and why these changes occur. This included information concerning the recovery patterns and how these patterns are facilitated in various areas of rehabilitation; 2) to teach the families home management skills. This included having the families learn compensatory skills to aid both themselves and the patient in better coping with whatever changes occurred in communication, psychological and social functioning; and 3) to create an environment which would allow families to vent their emotions and to share their problems and the solutions to these problems.

An invitation to attend the group was extended to the families of inpatients and outpatients who were currently receiving speech therapy and those patients who had plateaued and had been dismissed from speech therapy. For the families of the patients already dismissed from therapy, the group would provide a means of both review and exposure to new information and ideas. It was thought that those family members could serve as models of "I've been through it". To a limited extent, this program also served as a community referral source for other communication disorder centers and for independent speech pathologists who wanted to make this service available for their clients.

The format for these sessions called for the speech pathologist not only to provide information concerning communication disorders, but also to moderate sessions featuring a guest speaker. Guest speakers were invited to give the group an opportunity to discuss given topics in more detail. These speakers included a physiatrist, a rehabilitation nurse, a physical therapist, an occupational therapist and a social worker.

Prior to attending the meetings, each guest speaker met with the speech pathologist to discuss the goals for the program and to determine possible guidelines for the talk. This was done to avoid duplication of information and to familiarize the speaker with the group and their concerns. In order to facilitate group involvement, all speakers were urged to allot approximately 20 minutes to answer specific questions and to encourage group discussion.

Because the Mid-Maine Medical Center serves a large rural area some families would be required to drive up to 60 miles to attend these meetings. For the convenience of those persons required to drive long distances, the group was arranged to meet while the aphasic member was receiving individual and group therapy. This arrangement would also free all family members who might have otherwise been hesitant to have the aphasic individual stay home alone while they attended the group meeting. In addition, the patient would be available to participate in the counseling sessions when appropriate and the arrangement would allow the families to observe individual and group therapies as part of the home management training process.

The group met once a week for one hour for a total of ten weeks. The membership during the initial week was nine. The first group meeting was spent outlining the purpose of the group, a tentative schedule, the fee schedule, etc. The participants were given suggestions for topics to be covered and were encouraged to contribute ideas. This gave the members an opportunity to get acquainted and to share their individual situations. During this first session a question was raised about fees for the group. Many persons who attended had a family member who had

been dismissed from therapy and thus were not eligible for third party payment. The standard fee would have created a considerable financial burden for those families. As this problem became apparent, a decision was made to drop all charges for the services with the rationale being that this was a pilot program.

The remainder of the sessions were regularly attended by four persons with intermittent attendance by others. The distance traveled did not appear to hamper attendance as three of the regular participants drove between 45 and 60 miles to attend. The two factors which appeared to have the greatest influence on the drop in attendance were time conflicts with working schedules and finances. We were not able to schedule a time convenient for everyone, and the attendance was not sufficient to warrant scheduling two separate groups. Although no fees were charged, it was felt that the initial question of fees was responsible for at least three persons not returning.

In a subsequent meeting information was provided concerning recovery patterns and the manner in which each professional facilitates this growth and teaches the patient to use his skills to his best advantage. Participants were encouraged to interrupt with questions. It was thought that answering some questions initially would encourage questions during future sessions. Group participants were also given published materials which dealt with similar topics.

Speaker Input

In the following weeks each guest speaker led a discussion on family participation within a particular field of rehabilitation. The speech pathologist was present to help integrate how communication

affected the rehabilitation process within other therapies. The following includes a brief description of these discussion.

Medical Management

Speaker: physiatrist and rehabilitation nurse

A physician gave an overview of the more common causes of aphasia and related disorders and what has occurred neurologically. Diseases commonly associated with a CVA include cerebral embolus, myocardial infarction, hypertension and metabolic diseases such as diabetes. Since diseases and such conditions as convulsions and thrombophlebitis may influence the patient's rehabilitative process (Mossman, 1976) it is important for family members to be aware of the presence of any of these conditions and how they can best be controlled or prevented. This may include some type of active treatment such as diet control, physical exercises or medication. Families can therefore be deterred from developing misconceptions about the patient's medical problem. Families were given some guidelines to develop "constructive worrying" so that they would have the ability to determine what symptoms are considered warning signals of a stroke. The physician briefly described some tests used in diagnosis such as the CT scan and other terms associated with the CVA.

A discussion of problems encountered in home nursing was lead by a rehabilitation nurse familiar with problems commonly associated with the post cerebral insult patient. These problems included bowel and bladder care and the prevention and treatment of skin and circulatory problems.

Social and Emotional Adjustment

Speaker: social worker

The speaker stressed that aside from changes in physical functioning of the patient, the family must cope with psychological changes such as the changing of roles of family members, the adjustment of other relatives and friends, etc. This ability to cope and to be supportive may be aided by explaining some of the common reactions the patient experiences and why they occur. This may help the family to better understand the patient and help them to focus on the needs of the patient as he moves toward maximum recovery.

Emotional reactions often occur as a result of a disability. The individual may experience anxiety because of an inability to perform many daily functions, because of a fear of further medical problems or simply because he may not understand what has happened to him. It seemed to be especially helpful for the families of patients who were functioning at a maintenance level to share their experiences and their solutions with those families less adjusted to the situation.

Our team members found that often the patient or his family is hesitant to engage in social gatherings and tend to isolate themselves. Interaction with others may be facilitated by helping the families develop strategies to explain the patient's injury to friends and relatives. The family was urged to take the responsibility of teaching others to feel comfortable and to relate to the aphasic patient as a mature individual. This was facilitated by having the family members engage in role playing situations.

Communication

Speaker: speech pathologist

Included in this discussion was an explanation of what is meant by speech and language and how communication skills may be affected following a cerebral insult. Role playing situations were created in which a family member was required to relay or receive a message with some restrictions placed on the input or output channels. These exercises simulated communication deficits experienced by the aphasic patient. The purpose of this activity was to illustrate the frustration an aphasic faces and how he might compensate for the restriction. It was explained that the goal of treatment was not to "cure" the patient but to eliminate problems as much as possible and then to help the patient compensate for the remaining difficulties as best he can to allow him to lead the least dependent life.

The families were given suggestions on how to create a home environment conducive to successful communication for the patient. This included warning them of problems to expect and teaching them how to avoid them when possible. Rather than listing the "dos and don'ts" of communication, a videotape was developed to demonstrate errors which are commonly made as well as to illustrate ways to facilitate language and expression.

Impaired Gross Motor Functioning

Speaker: physical therapist

The purpose of this discussion was to inform the families why certain symptoms occur, to explain the purpose of training and to stress

the importance of home carryover to prevent further problems or the regression of skills.

The discussion included such topics as spasticity, range of motion and movements and coordination. The purpose of exercises was sited as being important for strengthening muscles and teaching balance. The family was made aware of the factors to be considered before ambulation is undertaken. Home management suggestions included guidelines for equipment care and use, transfers and how the home environment may be adapted for the person with a physical disability.

Activities of Daily Living

Speaker: occupational therapist

Activities of daily living were described by the speaker as those self care tasks performed each day. These would include such activities as eating, dressing, bathing and hygiene. Following brain injury the patient may be dependent upon others to a varying degree to complete these tasks as a result of physical or perceptual/cognitive impairments. This discussion focused on how these problems affect the patient's performance and how to best compensate for them. Beyond these basic activities the family was given suggestions for involving the patient as much as possible in other household routines such as cooking, cleaning and resuming hobbies if appropriate. Families were reminded that homemaking/cooking is not limited to women. Some men have always participated in these activities and if a man is unable to return to work for an undetermined amount of time he may be able to assume some responsibility in household tasks. Independence in activities of daily living appears to

be important for the morale of both the patient and his family. The families were counseled to allow and encourage as much self directed activity as possible.

Finances

Speaker: social worker

Often families of aphasic persons face serious financial problems. The major money earner may be unable to return to work. In addition, expenses might include bills for medical services, special equipment, medication or alternate living accommodations which represents expenditure of significant sums of money.

The families were instructed how to locate and apply for benefits to which they might be entitled. Specific programs were reviewed such as social security administration benefits. General approaches on how to deal with this type of bureaucracy and red tape was discussed.

Community Resources

Speaker: social worker

A common reaction observed has been for the aphasic patient to restrict his socialization to his family and those professionals providing supportive services. As he is dismissed from the various therapies, the patient may have few opportunities for outings. Most communities have a variety of programs which are related to work, socialization, and recreation. The family members may also be forced to find solutions for psychological and homemaking problems, as well as finding alternate living accommodations for the disabled person. The families were supplied with information concerning programs available in central Maine which

assist in finding services in the areas of psychological counseling, health care, housing, recreation, transportation and vocational counseling. A list of these specific programs are included in Appendix B.

III. PROJECT ASSESSMENT

Family Members

The effectiveness of the counseling sessions was determined by a subjective and an objective measure of attitude. During the latter sessions there was a certain degree of self internalization of the material as evidenced by the content of the family members' discussions. This included engaging in self analysis of attitudes, analysis of the patient's actions and their talking about the solutions to problems they ascertained in interacting with the patient.

A second assessment of the participants' attitudes was aided by the use of a more objective measure. Members were asked to fill out a questionnaire designed by the Massachusetts Rehabilitation Center in Boston (Appendix C). This questionnaire was mailed to the four regularly attending family members approximately one year after the conclusion of the group. They all responded and the following results reflects their attitudes. These responses gave the rehabilitation staff an indication of the long term benefits that the family counseling group provided.

Questions one and two dealt with the anxiety levels of the family member prior to the counseling group and all members responded that before attending the meetings they were fearful and worried and afterwards they felt better and less worried. Again a reduction of anxiety after attending meetings was indicated by the response to questions five and eight where the four members had felt more comfortable in visiting their relative and had a good idea what to expect from their relative. In terms

of education, three of the four persons responded that before attending the family counseling group they knew nothing about a stroke and notably one person had some incorrect information. All felt that they knew more about a stroke as a result of attending the meetings. Also each member felt that after the meetings they knew what the members of the rehabilitation team did for their relative and indicated that it was easier to ask questions of the staff members.

Although the Boston questionnaire was used as the evaluating tool for this group, Craig Institute in Denver, Colorado has also developed such a post session questionnaire (Appendix D) to be used as a means of determining whether the designated goals of a counseling group have been met and what changes in format might be advisable. Both questionnaires could be adapted according to the format of the educational program and the persons participating.

Rehabilitation Team

The reaction of the individual rehabilitation team members to the family counseling group was one of unanimous support. There was a common attitude that, indeed, there is no question of the need. The nature of the illness itself implies a need for family understanding. The onset of a cerebral insult is often sudden with varying degrees of long term effects resulting. The patient and the family are faced with dealing with those limitations but often having limited or no prior knowledge about this illness.

The staff members saw this family counseling group as an effective means of providing the family with the facts about the medical and

psychological implication of a cerebral insult, the remediation and recovery process which was to follow and some ways in which the family could aid in the rehabilitation of their family member. Staff persons commented that the families' greatest concerns had a general theme of "to what extent will this alter our entire lives". The staff provided information to try and answer some of their questions about future expectations. Whether or not the family could take this information and use it therapeutically was thought to be a by-product of the educational program, but how effectively the family used this information was, of course, up to the individual. There were some family members who wanted to become very active participants in their spouses therapies and the information presented seemed to enhance their skills in that respect. Another elderly gentleman seemed somewhat overwhelmed by all the information. Although he did not become involved in his wife's therapy to the extent that the others did, his basic knowledge about his wife's condition increased to the degree that he seemed to acknowledge her limitations and the reasons for some of her behaviors. By the end of this program he was verbalizing some ways in which he would be able to aid her in her physical and communication limitations upon returning home.

In addition, the rehabilitation team members indicated that these meetings gave them an opportunity to become more closely acquainted with the family, resulting in a better understanding of the patient's home environment prior to and following trauma. That information might be utilized to adapt therapy to meet those specific needs which arise as a result of those surroundings. These meetings were also deemed as an effective means of determining how capable and/or how interested the

family members were in becoming involved in the patient's therapies. The staff tried to capitalize on their interest as a way of extending the impact of individual therapy to the home.

Having the counseling program in a group format provided several advantages according to the staff. Because so much of the information concerning the patient's condition was new to the family member, each professional could act to reinforce the information by presenting examples, e.g. how a perceptual problem may affect the patient's performance within the different therapies and his behavior at home. The approach was also thought to be helpful in relating how the various rehabilitation programs are interrelated rather than separate entities and to give the families a sense of group support from the rehabilitation team members.

Although the group format has many merits it can not be used as a blanket approach to counseling. The staff members agreed that it must be used as a supplement to individual counseling which serves the families more immediate or individual needs. The physician and social worker also cautioned that not everyone can benefit from a group counseling approach. Some persons are hesitant to candidly discuss their family concerns within a group. Their needs could be more effectively met through independent counseling or by having a private conference in which all staff members would be available to jointly discuss a particular family's needs.

Suggestions for future groups included to continue encouraging family members to voice their suggestions of topics to be discussed. One staff person mentioned that aside from directly asking for suggestions, a written questionnaire could be given during the initial meeting to determine what specific concerns and attitude the family had about the aphasic

family member and related circumstances. It was suggested that after the rehabilitation staff presented the core topics, the family should be free to decide the topics for the remaining one or two sessions. One staff member suggested that an addition be made to the core speakers by having a previous patient and/or family member come and share their past experiences during their recovery process.

Speech Pathologist

As coordinator/clinician I support the views of the staff and the family that this group was a valuable tool. It provided the family with an opportunity to gain knowledge of a cerebral insult and the rehabilitation process which follows. This positive approach to patient rehabilitation was also evidenced by the added strength it afforded the entire team's efforts in treating the total patient. We were allowed a look at what positive forces and what inhibiting factors were present in the patient's environment and could prepare both the patient and his family accordingly.

Aside from the educational merits the group also allowed the families an opportunity to vent their frustrations and concerns in dealing with this crisis situation. Often there were no definitive answers given but there seemed to be a benefit in having another member share a similar kind of experience and explain some of the ways they have coped. Collectively, the members gained a measure of support just by being in the group. This process of identifying with others in a similar circumstance seemed to be helpful in alleviating the overwhelming feeling of "my problem is so unique". The group provided a form of sharing that is not always

available in a clinician/client relationship.

The opportunity for participation in a family counseling group should be available for all appropriate families of aphasic persons. However, it should not be imposed indiscriminately. Ideally, the family would be urged to attend the initial meeting to become acquainted with what the group could offer and then decide if they wished to join the group.

In terms of effectiveness, future groups could be improved by involving all the rehabilitation staff members in initial meetings to coordinate the discussions. This would act to develop a sense of continuity in the discussion and to reduce the redundancy of information. However, some overlap of material covered is helpful in relating how various rehabilitation programs are interrelated.

The problems resulting from a cerebral insult are many and may vary dramatically from patient to patient. Therefore, the curriculum within each series of counseling sessions must be flexible to meet the needs of those participants. Aside from the core of topics and speakers used, additional topics may be appropriate for a particular group. The information made available from the survey (Appendix A) will be used as a resource for additional topics and speakers for future groups.

Other considerations for future meetings include increasing the selection of published materials for the families so that they may have written materials available to review information covered during group sessions. Again the material suggestions obtained from the survey will serve as a resource (Appendix A). In addition, families might benefit from viewing films and/or audiotapes which demonstrate how to implement

the home management procedures (Appendix A). Videotapes of the patient group therapy sessions could also be presented to demonstrate how communication can be facilitated.

Although this program is strongly supported by the staff and the family group members, the future of this group is dependent on two factors. The inpatient and outpatient load fluctuates and at times is not sufficient for a family group. In addition, travel within a rural setting is often a problem in terms of the availability of a vehicle, the prohibitive road conditions during winter months and the cost of traveling from the outlying areas. One way of alleviating some of the traveling would be to increase the length of each meeting and reduce the number of times the group meets.

IV. CONCLUSION

The family counseling program was begun as a means of responding to the apparent educational and social adjustment needs of the families of our aphasic patients. The 10 sessions attempted to increase the family's understanding of the aphasic relative and the participants' evaluations confirms the value of this program.

Not all clinical settings are suited for conducting a family counseling group because of insufficient caseload or limited resources. However, it remains that the aphasic patient and his family are faced with the long term effects of that medical crisis. A family counseling group is a means of involving the family as a positive force in the rehabilitation regimen. Every patient is entitled to a treatment plan with the intent to achieve maximum recovery. Family understanding and involvement supports those steps in achieving the least dependent living status for the aphasic relative. A family counseling group is a viable means of achieving that end result.

Appendix A

SURVEY RESULTS

The percentage of affirmative responses for each suggestion is listed to the right of each item.

SUGGESTED TOPICS	<u>%</u>
Causes of a stroke	100
Psychological changes resulting from stroke	95
Definition of what is meant by "aphasia"	87
Physical management	83
Communicating with the aphasic	83
Types of aphasia	74
Dietary management of stroke victims	39
Family management and problems	30
Vocational planning	30
Home nursing	9
Sex counseling	9
Social activities	4
General relaxation	4
Social services available	4
Money management	4
Responsibility of the aphasic in communication	4
Coping with behavior changes	4
Community resources and placement options	4
Perceptual problems in activities of daily living	4
Driving and transportation	4

	<u>%</u>
Upper extremity treatment and equipment	4
Wheelchair handling - transfers - body mechanics	4
Therapeutic exercise	4
Ambulation	4
Diagnostic tests used by the physician	4
Death and dying	4
 GUEST SPEAKERS	
Physical Therapist	100
Occupational Therapist	100
Social worker	83
Nurse	83
Physician	75
Psychologist	58
Dietitian	25
Attorney	8
Transendental Meditation Instructor	8
Recreation Therapist	8
Home care nurse	8
Former patient and family	8
 FINANCIAL SUPPORT FOR THE GROUP	
No charge	39
Private	30
Medicare	22
Medicaid	17

	<u>%</u>
Veterans' Administration	9
Heart Foundation	4
Vocational Rehabilitation	4
Insurance	4
Institute for Rehabilitation Medicine Funds	4
TRANSPORTATION	
Private	96
Community service transportation	4
Easter Seal program	4
Veterans' Administration	4
MATERIALS FOR FAMILY	
American Heart Association, <u>Aphasia and the Family</u> . Dallas, American Heart Association.	65
_____. <u>Body Language</u> . Dallas, American Heart Association.	4
_____. <u>Diagnosis and Management of Stroke</u> . NY, NY, American Heart Association.	4
_____. <u>Do it yourself Again</u> . Dallas, American Heart Association (1967).	4
_____. <u>Essentials of Stroke Diagnosis and Management</u> . NY, NY, American Heart Association	4
_____. <u>Facts about Stroke</u> . Dallas, American Heart Association.	4
_____. <u>A Guide for the Family</u> . Dallas, American Heart Association (1969).	4
_____. <u>Strike Back at Stroke</u> . Dallas, American Heart Association.	4

	<u>%</u>
_____. <u>Stroke: Why do They Behave that Way.</u> Dallas, American Heart Association (1974).	17
_____. <u>Up and Around.</u> Dallas, American Heart Association.	4
Boone, D., <u>An Adult has Aphasia,</u> Danville, Ill: The Interstate Printers and Publishing, Inc. (1965).	26
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Buck, M., <u>Life with a Stroke,</u> Reprint from Dec. 1957 of Crippled Child Magazine, Chicago, Ill.: National Easter Seal Society.	13
Cohen, K., <u>Communication Aids for the Brain Damaged Adult.</u> Minneapolis, Minn.: Sister Kenny Institute (1977).	4
Cohen, K., <u>Communication Problems After a Stroke.</u> Minneapolis, Minn.: Sister Kenny Institute (1977)	22
Horwitz, B., <u>An Open Letter to the Family of an Adult with Aphasia.</u> <u>Rehab. Lit.</u> , 23:5:141-149 (1962).	4
Keenan, J., <u>First Aid for Aphasics.</u> Chicago: National Easter Seal Society (1974).	4
Lombardi, J., <u>Hardy, Helpful Hints for the Handicapped.</u> Chicago: National Easter Seal Society (1974).	4
National Easter Seal Society, <u>Understanding Stroke.</u> Minneapolis, Minn.: Sister Kenny Institute (1975).	4
Sister Kenny Institute Staff, <u>About Stroke.</u> Minneapolis, Minn.: Sister Kenny Institute (1975).	4
Taylor, M., <u>Special Problems of Hemiplegic Patients.</u> Reprint of paper presented at 1962 Annual Convention of National Easter Seal Society, Chicago: National Easter Seal Society	4
Taylor, M., <u>Understanding Aphasia, A Guide for Family and Friends.</u> New York: The Institute of Rehabilitative Medicine (1958).	61

FILMS AND AUDIOTAPES

- The Inner World of Aphasia. 16mm--color--24 min.--
rental or purchase, State Offices of the American
Heart Association or Berkley, California: Psychology
Exploration Film, 1600 La Loma Ave., 94709 1
- Stroke Counter Stroke. 16 mm--color--25 min.-- free.
State Offices of the American Heart Association. 1
- The Nature of Aphasia, by K. Pomerantz. Communications
in Learning, Inc. 2929 Main St. Buffalo, N.Y. 14214.
26 min--Handout--\$11.70 cost, rent \$4.60. 1
- Fred Bennet, Right Hemiparetic, 7½ min., color, \$120, rental
\$15.50, Minneapolis, Minn.: Sister Kenny Institute. 1
- Causes and Effects of Stroke, 36 color slides with cassette,
\$30, no rental, Minneapolis, Minn.: Sister Kenny
Institute. 1
- Rehabilitation of the Stroke Patient, 38 color slides with
cassette, \$30, no rental, Minneapolis, Minn.: Sister
Kenny Institute. 1
- Let's Start Again, Mr. Wilson, 24 minute, color, \$300, rental
\$15.50, Minneapolis.: Sister Kenny Institute. 1

Appendix B

COMMUNITY RESOURCES IN CENTRAL MAINE

Easter Seal

Occupational therapy, physical therapy and speech therapy

YMCA

Fitness, recreation, social groups

Lions, Kiwanis, Elks

Donations for equipment

Goodwill Industries

Employment for disabled

Salvation Army

Food, lodging, volunteers

Mental health centers

One to one, family or group counseling

Department of Vocational Rehabilitation

Medical, transportation, vocational testing, placement, equipment, tuition and sometimes money for attendant.

Community adult education program

Teach basic academics and crafts

Public libraries

Free movies and lectures, talking books

Department of Human Services

Direct payment of medical expenses for needy, nursing home placement

Social Security Administration

Monthly benefits paid to disabled workers

Town or city welfare

Rent, food, fuel orders, medical costs

Maine Employment Security Administration

Employment and job training, placement services, counseling for disabilities

Homemakers Services, Inc.

For elderly, handicapped, physically and emotionally ill and low income families and individuals and in crisis situations.

Provide child care, housekeeping, family finance and family medicine

Community Home Health Service

For sick and disabled who remain home. Provide nursing care, physical

therapy, speech therapy, medical and social services, dietary consult and assistance with medical supplies.

Social services

Boarding home placement

Community Action Center

Transportation, food stamps, family planning

Sheltered workshops

Job placement and job training

Veterans' Administration

Financial support of housing, medical, occupational therapy, physical therapy, speech therapy, counseling

Area agencies on aging

Low cost drugs, discount cards for restaurants and movies, health insurances, legal services, handy man, foster grandparent program, retired services volunteer program, property tax and rent refund

Diocesan of Human Relations

Socialization

Community Services and Information and Referral Services

General information and referral

Appendix C

GROUP EVALUATION FORM

- 1 Before attending this meeting I felt ____ because my family member has had a stroke.
 - (a) Fearful and worried
 - (b) Slightly concerned
 - (c) Not worried or concerned
 - (d) No answer

- 2 After attending this meeting I felt ____ about the stroke my family member has suffered.
 - (a) Better and less worried
 - (b) No change
 - (c) More worried
 - (d) No answer

- 3 Before this meeting I knew:
 - (a) Most everything about stroke
 - (b) As much as I needed to know about a stroke
 - (c) Some incorrect information about a stroke
 - (d) I still need more information
 - (e) No answer

- 4 As a result of this meeting:
 - (a) I know more about stroke than I knew before
 - (b) I learned nothing new
 - (c) I learned as much as I needed to know about stroke
 - (d) I still need more information
 - (e) No answer

- 5 After this meeting:
 - (a) I feel more comfortable visiting with my relative
 - (b) I feel the same about visiting my relative
 - (c) I will feel more uncomfortable visiting with my relative
 - (d) No answer

- 6 After this meeting:
 - (a) I now know what the members of the rehabilitation team do for my relative
 - (b) I understood the function of the rehabilitation team prior to the meeting
 - (c) I still would like more information about the function of the

rehabilitation team
(d) No answer

7 After this meeting:

- (a) It will be easier for me to ask questions of staff members
- (b) It will not be any easier for me to ask questions of staff members
- (c) I plan to ask questions as I did before the meeting
- (d) No answer

8 After this meeting:

- (a) I have a good idea of what to expect from my relative from now on
- (b) I am still unclear about what the future holds for my relative
- (c) No answer

Mass. Rehabilitation Hospital
Boston, Mass.

Appendix D

SAMPLE GROUP EVALUATION FORM

1. Patient's age
2. Patient's sex
3. Length of time since injury
4. Length of stay at Craig and/or Swedish
Inpatient_____ Outpatient_____ Both _____
5. Your relationship to patient
6. In what activities (work, school, recreation, therapy, workshop, family) is the patient involved now?
7. Are you involved with any agencies such as Vocational Rehabilitation, Social Services, volunteer groups, etc.?
8. Did you find the Craig Family Education Group helpful? In what way?
9. What topics were most beneficial? Least beneficial? (We have enclosed a list of topics presented.)
10. Are there any topics not presented that you would have liked?
11. Did you benefit from discussions with other families attending the group? In what way?
12. Did you feel there was enough time for questions? Did you feel that the staff answered your questions adequately?
13. Could the staff have been more responsive to your needs?
14. What comments would you like to make about the group or your stay at Craig?

Thank you, for your help.
Craig Institute, Denver, Colorado

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