

The Counseling Needs of the Families of Aphasic Patients

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It has been a frequent observation that aphasia is not only a problem in the use of language. Nor is it a problem whose effects are limited to the patient. Rather, as Buck (1969) has stated, aphasia is "a family illness." Reports by Biorn-Hanson (1957) and Malone (1969) have chronicled numerous psychosocial difficulties which are experienced by aphasic patients and their families. Role changes within the family unit, financial hardships, unexpected emotional responses--all are common sequelae of aphasia.

The family of an aphasic patient is generally considered an integral part of the rehabilitation team (Wepman, 1951), for it is the family who have the greatest effect on the patient's motivation and attitude and who must assume the burden for long-term care. It has recently been reported (Helmick, Watamori, and Palmer, 1976), however, that the spouses of aphasic patients typically underestimate the communicative impairments of their aphasic partners. That is, the spouses of aphasic patients tended to believe that the patients possessed better comprehension and expression skills than revealed on standardized tests of communicative ability. The need for a program of education and counseling for the families of aphasic patients is, therefore, readily apparent, for as Malone (1969) has observed, "the family cannot function as positive members of the rehabilitation team until they have been educated to the many and varied problems associated with aphasia and given some help in coping with these problems."

To date, no comprehensive study of the counseling needs of the families of aphasic patients has been undertaken. Therefore, the present investigation was initiated to delineate the counseling needs of these families.

Subjects

Five institutions were represented among the patients whose family members were included in the investigation. To allow adequate time for the families to receive counseling services, only those patients who were at least three months post-onset were included in the study. Time post-onset ranged from three months to ten years. As can be seen in Table 1, 21 spouses, 17 offspring, and three parents participated. The patients ranged in age from 24 to 79 years, while the family members ranged in age from 14 to 78 years.

TABLE 1
Subjects

Group	N	Male	Female	Time post-onset
Spouses	21	6	17	3 mos.-10 yrs.
Children	17	9	8	6 mos.- 3 yrs.
Parents	3	1	2	9 mos.-18 mos.

Results of Counseling Survey

All family members participating in the study completed a questionnaire; spouses, offspring, and parents. The questionnaire dealt with both the information and counseling received following the onset of aphasia, and what information and counseling ought to be made available to these family members.

Only the spouses of the patients were interviewed, in order to make a determination of the spouse's counseling needs and to probe more fully into areas of major concern to them. The interviews were limited to spouses because it was believed that, in most cases, the spouses shared the closest relationship with the patient.

Table 2 shows the percentage of spouses, children and parents who stated that they had received formal counseling. Formal counseling was defined as a specific time that had been set aside by a member of the rehabilitation team to discuss brain damage, its consequences and its effect on the family. All of the subjects believed that counseling should be made available to the families of aphasic patients, and 80% of the spouses thought that counseling should be offered continuously throughout the rehabilitation period.

TABLE 2
Offering of Counseling (% Responding Yes)

	S	C	P
Received formal counseling	81	59	100
Counseling was adequate	65	78	67
Counseling should be offered	100	100	100
Should be offered continuously	80	59	67

When asked who provided the counseling services (see Table 3), 94% of the spouses stated that they received counseling from the speech pathologist. It must be noted, however, that the subjects were referred to us by the speech pathologist. At least one-half of those completing the questionnaire also received counseling services from social workers or physicians.

TABLE 3
Who Provided Counseling? (% responding)

	S	C	P
Physician	59	50	100
Nurse	24	40	100
O.T.	29	50	67
Speech Path.	94	60	100
Social Worker	53	60	67
P.T.	35	50	67
Dietician	12	0	0

Table 4 shows that residual communication deficits were discussed with only 67% of the spouses. When asked if the prognosis should be discussed, even if it is not favorable, only one family member said that he would not want to be informed of the prognosis.

TABLE 4
Prognosis (% Responding Yes)

	S	C	P
Prognosis discussed	81	59	100
Residual communication deficit discussed	67	59	67
Prognosis should be discussed	95	100	100

As shown in Table 5, only 24% of the spouses had the opportunity to speak with families of other aphasic patients and 75% of these did not think that this was beneficial. Nevertheless, five of the children and one of the parents spoke with other family members and all of them thought that this was helpful. Few of the subjects participated in group sessions, but of those who did, half of the spouses and all of the children and parents felt that these sessions were beneficial. Almost one-half of the children, all three of the parents, and three-quarters of the spouses were provided with reading materials concerning stroke and aphasia. However, during the interviews many of the spouses commented that the reading materials were inadequate, and consequently many of them asked for additional readings.

TABLE 5
Alternative Forms of Counseling (% Responding Yes)

	S	C	P
Spoke with families of other aphasic patients	24	27	33
Was beneficial	25	100	100
Participated in group counseling	14	13	33
Was beneficial	50	100	100
Were provided reading mat'l.	76	44	100

With regard to changes in lifestyle, three-quarters of the spouses stated that there had been a change in the husband-wife relationship (see Table 6). One woman stated, "I have occasionally caught myself saying or thinking since J. 'died', because the person that I knew has died and he is not the same and it is not the same relationship. It is sort of a shock when you finally say it, but it is a reality." On the other hand, two subjects felt that their relationships had improved. One husband commented, "it (the relationship) is better in the sense that E. is not nearly as prone to argue or to be angry about things. In some aspects, as brutal as it sounds, there were certain benefits that came out of the stroke."

One question dealt with whether or not the family member had explained the patient's behavior to friends and acquaintances, to their children, or to strangers. As shown in Table 6, a majority of the subjects felt the need to explain the patient's behavior to friends. When asked what they told them, most replied simply with a statement that the patient had suffered a stroke. Few of the subjects provided directions to others on how to communicate more effectively with the patient.

TABLE 6
Changes in Life Situation (% Responding Yes)

	S	C	P
Relationship changed	76	47	0
Shift in responsibilities	76	94	67
Change in social life	67	82	67
Explained patient's behavior to:			
friends and acquaintances	81	87	67
children	71	--	--
strangers	67	20	33

As one might expect, a majority of the family members experienced anxiety and frustration (see Table 7). In addition, helplessness, hostility, and guilt were also felt. When asked how they dealt with these feelings, some family members said that they confided in close friends and in relatives while others said that they sought professional counseling services. One 34-year-old woman said she was ashamed of her feelings and felt guilty for thinking the way she did. Nevertheless, she said, "I wish that he had died. It would be so much easier."

TABLE 7
Emotional Responses (% Responding)

	S	C	P
Had experienced feelings of:			
anxiety	90	29	67
frustration	86	47	67
helplessness	57	29	33
depression	52	41	33
pity	52	18	0
hostility	38	24	33
guilt	33	12	33
shame	14	0	0

An overwhelming majority of the family members reported changes in relationships and shifts in responsibilities (see Table 6). However, the patient's emotional adjustment, depression, irritability, and fatigability were infrequently discussed with family members (see Table 8). Twelve of the patients were employed at onset and 75% of these received counseling regarding return to employment. Seventy-five percent of the spouses noted shifts in responsibilities to other family members, but finances and insurance were discussed with only 24% of these. It can also be noted on Table 8 that 95% of the spouses received counseling regarding speech and language impairments. Here again, it should be noted that the subjects were referred by speech pathologists.

In response to questions regarding whether or not the family members had been counseled on how to cope with physical, emotional, or communication problems (see Table 9), 29% of the spouses received information on how to cope with emotional problems; and 48% received information on how to facilitate communication. When asked if they would actively employ techniques taught to them in these three areas, 85% of the spouses stated that they would use such techniques to cope with physical problems, 95% stated that they would use techniques to aid in coping with emotional problems, and all of the spouses

said that they would use techniques taught to them to facilitate communication. Note, however, that a lesser percentage of the children and parents stated that they would use such techniques.

TABLE 8
Areas Discussed (% Responding)

	S	C	P
Received counseling re:			
Emotional adjustment	33	50	0
Patient's depression	43	56	33
Patient's irritability	19	50	0
Patient's fatigability	29	31	0
Returning to employment	43	13	33
Finances & insurance	24	13	33
Speech-language impairments	95	81	67

TABLE 9
Coping with Specific Problems (% Responding)

	S	C	P
Had been counseled re:			
Coping with physical problems	29	31	33
Coping with emotional problems	10	13	0
Facilitating communication	48	56	33
Would employ techniques for:			
Coping with physical problems	85	73	33
Coping with emotional problems	95	80	67
Facilitating communication	100	87	67

To find out how much the subjects thought they knew about aphasia, in general, they were asked the following: if you had taken a test on aphasia and the problems which accompany it, one week after the onset of the patient's aphasia, would your grade have been an "A", "B", "C", "D", or an "F"? Sixty-three to 69% of all three groups (see Table 10) stated that they would have received a grade of "D" or "F". The subjects recognized that they needed counseling and information as evidenced in their grades one week post-onset; but when asked if the same test were taken today, 85% of the spouses thought that they would have gotten a grade of "A" or "B". Fifty-six percent of the children believed that they would have also scored in the "A" or "B" range. Two of the parents felt they would have received a "B". From the responses to this question, it is apparent that the family members felt that over time they had added substantially to their understanding of aphasia.

TABLE 10
Understanding of Aphasia (% Responding)

Your grade on a test about aphasia taken:							
One week post onset			Today				
	S	C	P		S	C	P
A	0	12	0	A	32	31	0
B	21	19	0	B	53	25	67
C	11	6	33	C	0	31	33
D	11	25	33	D	11	6	0
F	58	38	33	F	5	6	0

The final question dealt with how much the family member was in need of counseling and information at onset. The subjects were required to rate their need on a five-point scale with one being "very much in need of counseling" and five being "none at all." As shown in Table 11, all of the spouses, all three of the parents, and 62% of the children felt that they needed counseling "very much" one week after the onset of aphasia in a family member. When asked how much they were in need of counseling at this point in time, 53% of the spouses stated that they were still in need of counseling; that is, they gave themselves a "1" or a "2". This finding is particularly striking when juxtaposed with the responses to the preceding question on which 85% of the spouses indicated that they now have a good ("A" or "B") knowledge of aphasia. This would seem to indicate that knowledge of aphasia alone is not an adequate base for coping with aphasia and the problems associated with it. Rather, the families of aphasic patients must be given support and direction in dealing with difficult situations and feelings.

TABLE 11
Need of Counseling (% Responding)

How much were/are you in need of support & information:							
At onset				Now			
	S	C	P		S	C	P
1 (very much)	100	62	100	1	42	19	67
2	0	6	0	2	11	6	33
3	0	25	0	3	26	19	0
4	0	6	0	4	5	44	0
5 (not at all)	0	0	0	5	16	13	0

Accuracy of Judgment

Both the spouse of an aphasic patient and a certified Speech Pathologist who was familiar with the patient's communicative abilities were asked to rate the patient's performance as normal, good, fair, poor, or unable on all the items of the "speaking", "understanding" and "reading" sections of the Functional Communication Profile (FCP) (Sarno, 1969) and items 1, 3, 4, and 6 of the "other" section (these four items were used as a measure of writing ability). Numerical values of 4, 3, 2, 1, and 0 were assigned to the ratings of normal, good, fair, poor, and unable, respectively. The Speech Pathologist's rating for each item was then subtracted from that of the spouse, and mean differences for overall communicative ability, "speaking", "understanding", "reading", and "writing" were determined. A mean difference of 0.5 was considered a substantial difference between the two ratings. A positive mean difference indicated that the spouse had overestimated the patient's performance, while a negative mean difference indicated that the spouse had underestimated the patient's performance.

Of the 18 spouses included in this study who had completed the FCP, 7 displayed a mean overall difference greater than 0.5. All of these spouses overestimated their aphasic partner's communicative ability. Table 12 presents the results concerning those spouses whose ratings differed substantially from those of the Speech Pathologist in at least one modality. Two findings are of note. First, only 39 percent of the spouses included in this study differed substantially from the Speech Pathologist in their judgment of overall communicative ability. Conversely, 50, 56, and 61 percent of the spouses differed substantially

in their rating of speaking, reading, and writing performance, respectively. Second, among those spouses who did exhibit a substantial difference in their ratings, no less than 80 percent overestimated their aphasic partner's performance in any given modality. This latter finding is consistent with that of Helmick et al. (1976) who similarly reported a tendency on the part of spouses to overestimate their aphasic partner's communicative abilities.

TABLE 12
FCP Rating Differences

	Differences > 0.5				
	Overall	Spkg.	Undst.	Rdg.	Wtg.
Overestimators	7	8	6	8	9
Underestimators	0	1	0	2	2
Total	7	9	6	10	11

Accuracy of Judgment by Confidence in Judgment

In addition to making judgments concerning their aphasic partner's level of performance, the spouses were asked to rate their confidence in their judgment item-by-item, on a 5-point scale where 1 indicated "100% certainty" and 5 indicated "just guessing." The percentage of items on which the spouses expressed "100% certainty" in their judgment was determined for the overall profile and each of the four modalities under consideration. Those spouses who expressed "100% certainty" on at least 75% of the items were designated as displaying "high confidence" and those who were certain of less than 75% of their judgments were designated as having "low confidence."

Table 13 displays the accuracy-by-confidence analysis of the data obtained. Note that of the 7 spouses who differed substantially from the Speech Pathologist ratings, 5 displayed high confidence in their judgments. Approximately the same proportion of those spouses with poorer judgment were highly confident of their assessment of their aphasic partner's speaking, reading, and writing abilities, and an even greater proportion were highly confident of their judgment concerning the patients' understanding. Among those spouses who displayed good judgment (differences less than 0.5) concerning their aphasic partner's communicative abilities, nearly one-third revealed low confidence in their ratings for understanding, reading, writing, and overall communicative ability. Speaking, the modality in which the spouses had the greatest amount of concrete information on which to base their judgments, was the notable exception, with all nine of the spouses who displayed good judgment being highly confident.

TABLE 13
Accuracy-by-Confidence Analysis

	Overall	Spkg.	Undst.	Rdg.	Wtg.
	Differences > 0.5				
High confidence	5	6	5	7	7
Low confidence	2	3	1	3	4
Total	7	9	6	10	11
Differences < 0.5					
High confidence	7	9	8	5	5
Low confidence	4	0	4	3	2
Total	11	9	12	8	7

Implications and Future Directions

As may be seen in Table 13, the accuracy-by-confidence analysis allows the differentiation of the spouses into four groups: (1) those displaying poor judgment (differences greater than 0.5) and high confidence, (2) those with poor judgment and low confidence, (3) those with good judgment (differences less than 0.5) and low confidence, and (4) those with good judgment and high confidence. One might suggest that the above ordering of these 4 groups of spouses represents a priority listing concerning counseling need. That is, those spouses who display poor judgment with high confidence are most in need of additional counseling, followed closely by those with poor judgment and low confidence. Those spouses displaying good judgment and low confidence might require less extensive counseling, while those with good judgment and high confidence may require little or no additional counseling. In addition, the type of counseling provided may differ for each group. For example, among the spouses with poor judgment, those with low confidence may require a great deal more emotional support than those with high confidence. To this end, the accuracy-by-confidence analysis is offered as a means of obtaining, at various intervals during the rehabilitation process, an indication of a spouse's understanding of the patient's communicative abilities and his/her attitude toward their understanding. Furthermore, this analysis may be employed as a more objective means of assessing the efficacy of our counseling services.

The accuracy-by-confidence analysis described in this paper has one significant limitation, however. This analysis has validity only after a period of time during which counseling has been provided to the family of the aphasic patient. All too often the spouse or family with special needs may go undetected for several weeks or months. Perhaps they may not be identified prior to the patient's being discharged from treatment and then are obscured by a steady stream of new referrals. With this as its rationale, a project is now underway which is seeking to determine if there is a constellation of factors (e.g. age, sex, severity of impairment, employment status, etc.) which will permit the early identification of those spouses who are likely to encounter greater difficulty adjusting to an altered life situation. Perhaps if we are able to predict which spouses are most likely to eventually settle into each of the four groups identified in this study, we will be able to develop differential counseling strategies which will enable us to more efficiently allocate staff time and to more effectively deal with the problems confronting the various groups into which the spouses of aphasic patients may be differentiated.

Acknowledgement

This project has been conducted in conjunction with the Medical Rehabilitation Research, and Training Center Number Nine, The George Washington University and has been supported by the Department of Health, Education, and Welfare, Office of Human Development, Rehabilitation Services Administration, Grant Number 16-P-56803/3-13.

References

- Biorn-Hansen, V. Social and emotional aspects of aphasia. J. Speech Hearing Dis., 22, 53-59 (1957)
- Buck, M. Expressive language problems of the aphasic patient which interfere with vocational rehabilitation. In The Vocational Rehabilitation Problems

- of the Patient with Aphasia. U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Service, Rehabilitation Services Administration, Washington, D.C.: Government Printing Office (1969)
- Malone, R.L. Expressed attitudes of families of aphasics. J. Speech Hearing Dis., 34, 146-151 (1969).
- Helmick, J.W., Watamori, T.S., and Palmer, J.M. Spouses' understanding of the communication disabilities of aphasic patients. J. Speech Hearing Dis., 41, 238-243 (1976)
- Sarno, M.T. Functional Communication Profile. Institute of Rehabilitation Medicine, New York University Medical Center (1969)
- Wepman, J.M. Recovery from Aphasia. New York: Ronald (1951).

Discussion

- Q: Were the families involved in stroke clubs?
- A: Relatively few. Many of our subjects and many of the aphasic patients that we treat had gone to local stroke clubs and had dropped out because they were very unhappy with the emphasis on social activities. The primary problem appears to be that the stroke clubs try to please everybody and as a result they tend to better meet the needs of right CVA patients than those of left CVA patients. We have been trying to restructure our own aphasia groups to take advantage of some of the successes that various laryngectomee clubs have experienced using a mixture of treatment and some socialization.
- Q: I'm a little concerned. It seems to me that the emphasis on this particular study and of future studies is providing a sufficient amount of information to spouses of the aphasic patients, and, if this is true, I'm a bit hesitant to assume that this is indeed the main goal that we should have for providing services to the families.
- A: If you will recall, some of the areas that we examined on the questionnaire dealt with things like emotional adjustment, insurance, and finances; sexual adjustment was also included. We are also hoping to look at factors such as nurturance. We are working with people in our family center and psychiatry to be able to look at other aspects and other factors regarding the spouses adjustment. No, we are not concerned just with information.
- Q: It has been my observation that there is a great socio-economic factor here in terms of whether the spouse seeks out information; that is, people who come from a professional background tend to know that they should expect counseling and so forth, whereas those who have never dealt with that kind of environment have no knowledge that this is something that they should expect and seek out. Do you find that educational or socio-economic factors are influencing which subjects have received counseling?
- A: We have not specifically analyzed the data in that regard, but I would concur with your observation. I would like to expand on this, however, if I may use an example from a study of the counseling of laryngectomees. It has often been said that information is provided in pre-operative counseling, but that the patients and their spouses hear nothing after the word cancer has been mentioned. I don't buy that argument. I think we as professionals need to be sensitive to that sort of thing and, to make this germane to your question, I think that we need to be cognizant of factors such as you have mentioned. We cannot expect our patients and their families to ask for counseling and information. Rather, we must be aggressive in making these services available.

Q: Was the counseling done person to person or by phone?

A: All of the counseling was done person to person.

Q: Do you feel that the Speech Pathologist is trained and qualified to handle all of the things that may come up?

A: I don't think that we are, but that's not to say that perhaps we shouldn't be. There are, of course, professionals with such training, and we need to involve them when we encounter serious problems. The key, it seems to me, is for us to be sensitive to problems which may arise, to recognize our limitations in dealing with these problems, and to know our referral sources.