

Comparative Family Perspectives on Aphasia:
Diagnostic, Treatment, and Counseling Implications

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The impact of stroke syndromes and aphasia on individuals and their families has received considerable attention in the literature of speech-language pathology and other professions. The research agrees that language prognosis and therapeutic progress is dependent on the aphasic person's psychological renewal and on his maintenance of social contact, as well as on the nurturance of the supportive people in his environment.

The family members' supplemental role in language therapy (Rolnick and Hoops, 1969; Taylor, 1964; and Goodkin, 1969) and their role as a "therapeutic agency" (Wepman, 1968) contribute significantly to the speech-language pathologist's function of informing, treating, and counseling. Darley (1972) noted the considerable role of the speech-language pathologist as a counselor of stroke families, and noted the lack of available data to guide these efforts. Recent efforts in the literature suggest the need for providing knowledge of the language deficit to the family (Schuell, Jenkins, and Jimenez-Pabon, 1964) and to analyze spouse ignorance of the language dysfunction (Helmick, Watamori, and Palmer, 1976). More recently, assessment tools and strategies have been developed to measure family attitudes, needs, and change (Pieras, Gurland, Chwat, and Chapey, 1981) and analyses of spouse and child knowledge and feelings have been documented (Chwat, Gurland, Chapey, and Pieras, 1980). To date, however, no study cites the comparative knowledge and relative needs of spouses and children who frequently live with, accompany, or assume financial, emotional, or functional responsibility for their afflicted family member (Chwat, Chapey, Gurland, Pieras, 1980). This study examines the knowledge and needs of the spouse and child in the aphasic family unit vis a vis the linguistic impairment. The analysis provides additional information towards establishing a comprehensive model of family counseling for the speech-language professional, and makes available objective data about the awareness of family members significant to aphasia rehabilitation.

METHOD

Subjects. Three groups of subjects were evaluated in the present study: a group of 14 persons with aphasia who had suffered single left CVAs with right hemiplegia, their spouses, and an equal number of their children. The aphasic subjects consisted of nine males and five females who ranged in age from 54 to 76 years, with a mean age of 64.4 years (Table 1). Months post onset ranged from 6 to 24 months, with a mean of 15.6 months. Educational level ranged from 8th grade through Masters.

Table 1. Characteristics of aphasic subjects.

Subject	Sex	Age	MPO	Education (years)
A1	F	64	23	12
A2	M	54	13	College
A3	M	76	24	College
A4	M	76	24	College
A5	M	68	15	Masters
A6	M	64	11	12
A7	M	68	20	8
A8	M	61	13	10
A9	F	68	16	9
A10	M	68	6	Masters
A11	F	56	17	12
A12	M	56	14	12
A13	F	57	13	12
A14	F	66	10	13

N = 5 females Age range: 54-76 years MPO range: 6-24 months
 9 males mean: 64.4 years mean: 15.6 months

Education range: 8-Masters
 mean: 13.1 years

Table 2. Characteristics of spouses of aphasic subjects.

Subject	Sex	Age	Education	Length/ Marriage	Employed
S1	M	63	College	41	Yes
S2	F	40	College	29	No
S3	F	70	12	52	No
S4	F	72	14	27	No
S5	F	65	12	44	Yes
S6	F	57	12	35	Yes
S7	F	65	11	28	Yes
S8	F	58	12	38	Yes
S9	M	68	11	46	No
S10	F	65	12	41	No
S11	M	55	11	23	Yes
S12	F	55	12	32	Yes
S13	M	58	12	35	Yes
S14	M	70	12	41	No

N = 5 males	Age range: 40-72	Education range: 11-16 years
9 females	mean: 61.5	mean: 12.5 years
Marriage range: 23-52 years.		Employed: 8 Yes
mean: 36.6 years		6 No

The spouses ranged in age from 40 to 72 years, with a mean age of 61.5 years. Educational level ranged from 11th grade to 2 years of college; length of marriage per couple ranged from 23 to 52 years prior to the stroke, with a mean of 36.6 years of marriage (Table 2).

The children consisted of 4 males and 10 females who ranged in age from 18 to 49 years, with a mean age of 31.9 years. Four subjects lived with their parents, while ten did not live at home. All subjects had at least three face-to-face child-parent contacts per week. Educational level ranged from 12th grade through doctorate (Table 3).

Procedures. Seven subtests of the Minnesota Test for Differential Diagnosis of Aphasia (Schuell, 1965) were administered to each of the aphasic subjects. The Functional Communication Profile (Taylor-Sarno, 1965) was completed for each subject prior to direct clinical examination with the MTDDA.

A 38-item questionnaire (Chapey, Pieras, Gurland, Chwat, 1981) was administered to spouses and children of the aphasic subjects. The questionnaire (Appendix) consisted of items designed to test information level with regard to content, form and function categories (Bloom and Lahey, 1978). Questions utilized a 5-point rating scale ranging from Almost Always to Almost Never, rank order selections, and descriptive statements.

Data analysis centered on multiple correlations between professionally administered objective measures of aphasia and spouses' and children's perceptions of aphasia based on scores obtained from the questionnaire. In addition, rank order selections and descriptive responses were analyzed according to percentage of response for each item on the questionnaire.

RESULTS

Table 4 presents the results of the correlation calculations between scores on the questionnaire and those on the MTDDA and the FCP. The correlation coefficient obtained between scores based on 21 items from the spouses' questionnaire and the MTDDA is .65, while the correlation coefficient obtained between scores on the spouses' questionnaire and those from the FCP is .71. Both correlations are significant at the .01 level. The correlation coefficient obtained between scores based on 21 items from the children's questionnaire and the MTDDA is .76, while the correlation coefficient obtained between scores on the children's questionnaire and those from the FCP is .68. Both correlations are significant at the .01 level. The correlation coefficient obtained between scores on the spouses' questionnaire and those on the children's questionnaire is .80, which is significant at the .01 level. This indicates a positive relationship between the spouses' and children's perceptions of the language deficit and objective measures obtained from traditional testing procedures administered by trained professionals. Additionally, the relationship between spouses' and children's perceptions of the linguistic impairment is positive.

The rank order and descriptive responses reveal the following results. The data generally indicate that both spouses and children of aphasic persons do not discern particular factors that influence word difficulty in expressive language, although all admit expressive linguistic difficulties to varying degrees. Neither group cites specific factors relative to production difficulty or ease; however, individual subjects in both groups

associated ease of word production with the relative degree of speech automaticity (e.g., vulgarisms, concretisms, rote language).

Table 4. Correlation coefficients measuring the relationships between scores on the questionnaire and those on the MTDDA and the FCP.

	Correlation	
	MTDDA	FCP
Scores obtained on spouse questionnaire	.65	.71
Scores obtained on children's questionnaire	.76	.68

Results also reveal that spouses and children are aware of compensatory strategies used by aphasic subjects to aid their linguistic expression and to elicit aid with comprehension. Techniques cited most frequently by spouses for aid with expression are delay (80%) and word description (40%); those cited most frequently by children are delay (69%) and sound association (46%). Techniques cited most frequently by spouses and children for aid with comprehension are facial expression (71%) and asking for repetition (38%).

All spouses and children agree that certain circumstances elicit better linguistic communication from the aphasic subjects than others. While most spouses and children agree that familiar surroundings (61%) and familiar people (67%) are most conducive to communication, a considerable number of subjects (67%) in both groups are unaware of specific places that would facilitate communication. Some subjects in both groups note that the aphasic person's communication varies with emotional state and increases after speech-language therapy (50%). Perceptions with respect to opportunity for communication differ between spouses and children. Spouses generally report reduced communication opportunities with equivocal reports concerning increases or decreases in the aphasic person's desire to communicate since the stroke. Children report increased communication opportunities for their aphasic parents, who, they believe, are less motivated to communicate since stroke.

Additional indications of linguistic motivation and communicative function are demonstrated in the spouses' and children's perceptions of the aphasic person's use of language for arguing, complaining, and giving directions. In a majority of cases (56%), the aphasic person is using language to argue, complain, and give directions; both spouses and children agree that the content of this language focuses on physical condition and pain, boredom, when communicatively frustrated, and when confronted with the inability to maintain life as before. More than half of the spouses and children (52%) note that the aphasic person confides his/her problems in a family member or close friend.

More than one-third (36%) of spouses and children are unaware of strategies they could use to facilitate the aphasic person's linguistic communication, feel inadequate to the task, or feel that that is the role of the speech-language pathologist. Most of the same respondents are unaware of ways to modify the home environment in order to motivate increased communication. However, about half (54%) of the spouses and children have initiated self-discovered structured communication with the aphasic family member (e.g., providing books, "second-guessing," "telling him to slow down," "watching for gestures," repetition, and "speaking for her"), with some family members following techniques or home practice recommended by the speech-language pathologist. Only 21% of the spouses suggested general ways to improve the communicative potential of the home environment, whereas 71% of the children recommended ways to increase and improve communicative contact.

The majority (67%) of the spouses and children report that the shared language content between themselves and the aphasic subjects is mostly concerned with familiar issues including family, business, and health topics; more of the spouses (44%) than children (30%) believe their shared language content has changed since the stroke. Only one spouse reports discussing stroke-related issues with the aphasic subject. Forty per cent of the children no longer confide in or discuss potentially upsetting issues with their aphasic parents, and an overwhelming majority (80%) of the children are unlikely to discuss the language impairment directly.

Responses to the question, "What is aphasia?" reveal the following results. Both spouses' and children's descriptions of aphasia are largely symptomatic. Only one child responded with an etiologically based definition; of the spouses, two said aphasia is synonymous with stroke, and one noted that aphasia is due to "illness." Symptomatic descriptions often include problems with speech, an inability to speak while understanding is intact, difficulty with thinking rate, inability to read and write, and forgetfulness and inability to verbalize thoughts. Subjects from both groups report emotion-laden descriptions of aphasia, indicative or personal frustration and anger ("It's the worst sickness," "Hell," "A terrible disease").

Sixty-four per cent of the spouses and children report that they do discuss the language impairment with members of other stroke families with some frequency, most often at stroke clubs, and consider this type of information-sharing important to the adjustment of a stroke family.

DISCUSSION

These results can be viewed from three clinical perspectives: diagnosis, therapy, and counseling. In spite of a vague, incomplete definition of aphasia, spouses and children are able to describe specific functional behavioral components of the aphasia syndrome as demonstrated by the significant correlations with professionally administered measures of linguistic impairment. The demonstrated validity of the questionnaire augments traditional aphasia assessment procedures currently available to the speech-language pathologist. Additionally, there is strong agreement between spouses and children regarding most aspects of the linguistic impairment. Further, spouses and children generally demonstrate commensurate levels of knowledge and ignorance. Family members, therefore, appear to play a considerable role in clinical

diagnosis and prognosis above and beyond the medical and personal history they usually provide.

Where spouses and children are aware of either the compensatory strategies used by aphasic persons to aid linguistic comprehension and expression, or those that the family members themselves use to augment communication, the questionnaire demonstrates additional usefulness as a diagnostic tool. That is, it informs the clinician of cueing strategies that have been developed apart from therapeutic intervention which may serve as a baseline for therapeutic procedures. Where the questionnaire indicates that family members are ignorant of strategies to aid the aphasic person, the clinician is directed to specific ways to help the family members identify and reinforce those strategies. The importance of familiarity with surroundings, people, and topics to aid functional communication is confirmed by virtually all family members. The specification of these variables provided by the questionnaire is essential to establish functional and comprehensive therapeutic intervention techniques, a pragmatic approach which has already had broad application in the child language literature (Bloom and Lahey, 1978; Holland, 1975; Bates, 1976).

It is interesting that spouses report reduced communication opportunities, while children cite the aphasic person's diminished desire to speak in spite of equal or increased communication opportunities. The resolution of this discrepancy and identification of real obstacles to communication for the aphasic person suggests an important family counseling role for the speech-language pathologist.

Family members' definitions of aphasia are highly related to their emotional perceptions. It is notable that only one subject from both groups of family members responded with a relatively complete definition of aphasia. No respondent, for instance, included comprehension difficulties in his/her definition of aphasia. Indeed, for many respondents, definitions were completely inaccurate. This information, accompanied by the reports of avoidance of discussion of the language impairment, stroke-related issues, and other problems with the aphasic person, underscores the professional's role in defining the aphasia problem for the family and for the aphasic person, in order to facilitate their understanding, management, and acceptance of stroke. The speech-language pathologist's particular expertise in aphasic disorders makes him/her of singular significance in this area. Given the spouses' and children's positive reaction to the structured interview, the questionnaire has potential as a tool for the clinician in achieving rapport with the family, guiding counseling procedures, and providing a measure of accountability.

Variability in this study may result from several factors, including the degree of language and physical impairment for the aphasic person, the time post-onset, sex distribution of aphasic person and family members, pre-stroke expectations of the family, and presence and age of other siblings. A factor analysis would be helpful to clarify stronger generalizations. What emerges from spouses' and children's responses to the questionnaire is a more complete analysis of the aphasic person's functional communication outside the clinical environment and information that may contribute to more comprehensive family-oriented aphasia rehabilitation by the speech-language pathologist.

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APPENDIX

APHASIA IMPACT RATING SCALE (Spouses)

Language Analysis of Perspectives of Spouses of Aphasics

1. Can your spouse
 - a. define words
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 - b. name objects, events, and relationships when they are presented?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 - c. complete an open-ended sentence such as "The sky is ---"
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 - d. produce rote, or well-learned material such as counting, naming days of the week
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 - e. recognize the correct word which is offered to him/her (for example, if he/she was holding an orange and couldn't name it, and you said, "Orange," could s/he recognize it?)
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 - f. repeat names
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
2. Can your spouse follow changes in the topic of conversation—for instance, if you are talking about dinner, and then you switch to talking about a baseball game, can s/he follow that?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
3. Can your spouse understand what you say?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
4. Are there particular types of words which your spouse finds easiest or hardest to say?

5. Is your spouse able to
 - a. construct phrases and sentences?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 - b. use a variety of sentence types such as declaratives and questions?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 - c. use articles, prepositions, pronouns, and conjunctions (such as a, of, me, or, and)?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never

- d. use word-endings such as plural-/s/, possessive-/s/, past-/ed/
for example, Mary's, parents, walked)?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
6. When s/he has difficult thinking of a word s/he wants, which of the following behaviors does s/he use? (Rank the behaviors in the order in which they are used; 1 is the most, 5 is least)
- ___ delay
___ a sound associated to the sound s/he is trying to use
___ a word that is related in meaning to the word s/he is trying to use
___ a description of the word
___ a generalization
7. When s/he has difficulty understanding a word, which of the following behaviors does s/he use? (Rank the behaviors in order in which they are used; 1 is most, 6 is least)
- ___ facial expression
___ asks for repetition
___ offers an earlier response
___ freely admits that s/he doesn't understand
___ makes an accurate, but associated response
___ makes an irrelevant response
8. Is your spouse aware of errors when s/he makes them?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
9. Does your spouse use the telephone?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
10. Does your spouse answer the telephone when it rings?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
11. Does your spouse look up telephone numbers in the directory?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
12. Is s/he able to memorize some telephone numbers?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
13. Does your spouse read the daily newspaper?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
- How has this changed since the stroke?
considerably ___ ___ ___ ___ ___ not at all
14. Does your spouse read magazines?
___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
- How has this changed since the stroke?
considerably ___ ___ ___ ___ ___ not at all

15. Does your spouse watch television:
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all
16. Does your spouse go shopping?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all
17. Does your spouse handle money on his/her own?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all
18. Does your spouse visit friends?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all.
19. Does your spouse talk about the past?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all
20. Does your spouse talk about the future?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all
21. When s/he speaks, is what s/he says appropriate to the situation.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all
22. Can your spouse overcome obstacles in communication? That is, when
 communication stops or gets difficult, can s/he respond and keep the
 conversation going?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
23. How often do people in your family talk to your spouse?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
24. How often does your spouse talk to others?
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
 How has this changed since the stroke?
 considerably ___ ___ ___ ___ ___ not at all

25. When would you say your spouse does the most talking?

Why?

26. Where is the best place for your spouse to talk?

27. Does your spouse have more or less of an opportunity to talk since the stroke? More Less

28. How has your spouse's desire to talk changed since the stroke?

29. Does your spouse ever argue? Yes No

About what?

30. Is your spouse able to give directions?
 almost always usually sometimes rarely almost never

31. Does your spouse complain often? Yes No

About what?

32. Does your spouse tell his/her troubles to a certain person? Yes No

To whom, and why?

33. How do you aid your spouse's understanding and/or production of speech?

34. What could you change around the home so that your spouse would enjoy talking more?

35. When you are together with your spouse, what sorts of things do you talk about?

How has this changed since the stroke?

36. In your own words, what would you say aphasia is?

37. If a stranger were to visit your spouse, how would you prepare him?

38. Suppose I were to live here; what would you tell me it is like to live with a person who has aphasia?
