

Environmental Impact of Aphasia: The Child's Perspective

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The devastating effects of aphasia on individuals and their families have been reported in the literature of speech pathology as well as in that of other disciplines (Malone, 1969; Broida, 1979). Because aphasia affects the entire family, speech pathologists devote much time to counseling family members on behalf of the aphasic person's psychological and linguistic intervention. However, as Darley (1972, p. 16) observes, "no data about the influence of these factors are available." A majority of professionals agree that the aphasic person's language performance, the patient's psychological outlook and motivation, and all aspects of recovery are influenced by the caring people around him and in his maintenance of social contact (Wepman, 1951, 1968; Turnblom and Myers, 1952; McBride, 1969; Keenan and Brassell, 1974; Griffith, 1970; Eisenson, 1973; Carpenter, 1974; Ritter, 1976; Darley, 1977; Hutchinson and LaPointe, 1977; Metzler and Jelinek, 1977; Wertz, 1978; Mogil, 1978; Brookshire, 1978). Indeed, family members' interest in the patient and their desire to see improvement in language ability will frequently influence the progress made during intervention (Chapey, 1981).

Although current literature reports data concerning spouse feelings (Malone, 1969), spouse participation in therapy (Goodkin, 1969), and spouse and family counseling (Malone, 1975; Malone and Malone, 1977; Porter and Dabul, 1977; Czvik, 1977; Linebaugh and Young-Charles, 1978; Newhoff and Davis, 1978; and Broida, 1979), little attention has been given to the children of aphasic persons. These individuals frequently live with, accompany, or assume financial, emotional or functional responsibility for their afflicted parent. However, the effects on and perceptions of the children of aphasic individuals have not been documented in an area where our field is called upon to provide significant information and counseling. Therefore, the purpose of this study is to examine the expressed attitudes of children of aphasic persons concerning the environmental impact of aphasia so as to provide the clinician with a therapy and counseling model, and to examine the need for the speech pathologist's expanded role in aphasia rehabilitation.

METHOD

Subjects. Two groups of subjects were evaluated in the present study, a group of 16 persons with aphasia who had suffered singular left CVAs with right hemiplegia and an equal number of their respective children. The aphasic subjects consisted of 9 males and 7 females who ranged in age from 46 to 71 years, with a mean age of 60 years (Table 1). Months post onset ranged from 2 to 24 months, with a mean MPO of 12 months. Educational level

ranged from 8th grade through one year of college. Language ability as assessed by 7 subtests of the Minnesota Test for Differential Diagnosis of Aphasia revealed scores ranging from 15 to 83 (18% to 99%) (Table 1).

Table 1. Aphasic subject distribution with respect to sex, age, MPO, level of education and MTDDA scores.

Subject	Sex	Age	MPO	Education (years)	MTDDA Scores
A1	F	62	13	12	54 (64%)
A2	M	71	3	8	72 (86%)
A3	F	56	5	12	54 (64%)
A4	F	71	4	12	43 (51%)
A5	M	61	21	12	67.5% (80%)
A6	M	46	18	13	78 (93%)
A7	M	50	24	13	82 (98%)
A8	M	57	7	12	78 (93%)
A9	M	67	24	12	83 (99%)
A10	M	67	12	13	72 (86%)
A11	M	56	9	12	45 (54%)
A12	F	65	15	13	83 (99%)
A13	F	63	12	12	23 (27%)
A14	F	65	13	12	66 (79%)
A15	F	46	8	13	60 (71%)
A16	M	55	2	12	15 (18%)

The children consisted of 4 males and 12 females who ranged in age from 15 to 41 years with a mean age of 26 years. Ten subjects lived with their parents, while 6 did not live at home. All subjects had at least three face-to-face child-parent contacts per week. Education level ranged from 10th grade through post-Masters (Table 2).

PROCEDURES

Experimental materials were administered to children of aphasic individuals and consisted of a 50-item questionnaire (Pieras, Chwat, Gurland, Chapey, 1981). The questionnaire (Appendix A) was divided into the following nonlinguistic categories: role change, irritability, guilt, altered social life, financial, job-school neglect, health, over-solicitousness and rejection. Children were instructed to respond by checking appropriate markings on a five-point rating scale ranging from Almost Always to Almost Never. Items were derived from articles and books in clinical aphasiology literature. Data analysis centered on the percentage of responses in each above category.

RESULTS

Major results indicate that children of aphasic persons experience marked modifications in nonlinguistic components of their own lives since the stroke.

Table 2. Children of aphasics with respect to sex, age, living at home, frequency of parent-child contact, and educational level.

Subject	Sex	Age	Living at Home	Frequency of Parent-Child Contact (per wk)	Educational Level (years)
N1	F	23	yes	daily	post B.A.
N2	F	38	yes	daily	11
N3	F	17	yes	daily	11
N4	F	33	yes	daily	post M.S.
N5	F	25	yes	daily	15
N6	M	19	no	3	12
N7	M	16	yes	daily	10
N8	M	20	yes	daily	15
N9	F	41	no	3	14
N10	M	39	no	3	16
N11	F	15	yes	daily	10
N12	F	31	no	3	M.S.
N13	F	36	no	daily	M.S.
N14	F	23	no	3	M.S.
N15	F	18	yes	daily	12
N16	F	18	yes	daily	13

Role Change. Children of aphasic individuals experience the greatest amount of role change in playing the role of parent, in bearing a greater share of responsibility than other siblings, and in being responsible for household chores. Indeed, 11 (68%) of the respondents experienced such a role change at least some of the time. In addition, 62% of the children find that they guide their parent in making medical decisions as well as in their personal care. Fifty percent have the responsibility for making financial decisions for their parent. Only 31% find that they are responsible for planning their parent's social activities, and only one respondent indicated responsibility for younger siblings. Therefore, the children surveyed did, in fact, demonstrate some degree of role change subsequent to their parents' aphasia.

Irritability. Approximately 50% of the respondents reported that they lost patience with their parent and felt irritable after spending time with their parent. In fact, more than a third reported that making visits to their parent was anxiety-provoking. The situations which children found most irritable were assuming responsibility for household chores and planning their parents' social activities.

Guilt. Factors which contributed to their parent's stroke were ranked by children as follows: general health, occupation, relationship with children, self-imposed stress, relationship with others, financial obligations, and household responsibilities. Thus, children perceived physical health, relationships, and obligations as contributing factors to their parents' strokes. One-third of the children also indicated that they interacted with their parent a sufficient amount of time, a third felt that the interaction was excessive, and a third felt it was insufficient.

Altered Social Life. Thirty-eight percent of the children felt that their social lives had changed considerably since the stroke, and that the care of their parent frequently took time away from their own social activities. Fifty percent noted that their social life remained unchanged. Eighty-eight percent reported that their parent expected them to spend time with them, and 100% of the children actually spent more time at home than they did prior to the stroke.

Relationships with family members and friends were altered; 38% of the children's conversations with family members were frequently occupied with discussion of the parent's problem and/or with the child's difficulty in handling it. Outside the immediate family, half of the children were occupied with discussions of their parents' problem and/or difficulty in handling it, and 50% were not. However, one-third of the children perceived both family's and friends' reactions as tolerant or annoyed, as opposed to interested.

Individuals frequently providing emotional support to the children ranked as follows: self, other parent, friends. Occasionally the following individuals also provided support: psychotherapist, spouse, physician, and speech pathologist. Somewhat more than half (56%) of the individuals who typically visited the child at the parent's home were still likely to visit. Since the stroke, 81% of the children frequently involved their aphasic parent in a social situation.

Financial. Few if any children assumed financial responsibility, found it necessary to seek additional income, or needed to curtail other activities to meet their parents' medical and/or rehabilitation expenses. The financial status of the family was substantially altered in 63% of instances even though 69% were reimbursed by one or more health insurance plans. The other parent was most frequently responsible for medical and/or rehabilitation finances. Few unaffected parents, however, found it necessary to seek additional income to meet these expenses.

Job/School Neglect. Post stroke, 62% of the children found it difficult to concentrate on school and professional work, while 44% took time from job and/or school for direct parent care, experienced decreased performance in school and/or work because of concern about their parent, and found that their professional and/or educational decisions were influenced by considerations about their parent's future; however, instructors and/or employers rarely or never complained about the child's performance.

Health. The emotional health of children was frequently affected (56%); whereas physical health of these individuals rarely was (13%). As a result, 25% have sought professional counseling and/or psychotherapy to deal with the strain of their parents' illness.

Oversolicitousness and Rejection. Many children observed that as a result of stroke, they were protective of both their aphasic parent (69%) and their nonaphasic parent (56%). However, many (88%) also tried to be tolerant of their impaired parent and treated them as usual. Slightly more than a third of the children stated that they had a greater share of responsibility than their nonaphasic parent, but only one child felt that they were neglected by their nonaphasic parent because of his/her preoccupation with the aphasic parent.

DISCUSSION AND CONCLUSION

Findings of the present study suggest commonalities pointing to a family-oriented aphasia syndrome; the need for aphasia to be perceived as a family crisis; the importance of including children of aphasic persons in language treatment, and the importance of counseling to the stroke family.

Findings also indicate a need for identification and remediation of selected nonlinguistic variables profoundly affecting these parent-child interactions. This questionnaire has potential for pre-interview assessment of the children of aphasic persons, measuring family attitude change over time, and for guiding the clinician in structuring counseling procedures and evaluating therapeutic progress. In addition, the administration of the questionnaire prompted several children to comment that it forced them to rethink the nature of their parents' problem, their relationship with their parent vis-a-vis the stroke, and the potential helpfulness of discussing the family crisis with members of other stroke families.

Individual variability in the present study may result from a number of factors which need further study and clarification in subsequent research. These factors include: months post-onset, severity of the language and physical impairment, the child's non-stroke-related responsibilities and premorbid expectations, existence and age of other siblings, frequency of child-parent interactions, sex distribution of parent and child, and emotional proximity. The questionnaire should also be factor-analyzed so that stronger generalizations can be drawn from the results.

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DISCUSSION

- Q: I am questioning the range of ages of the children. In dealing with this kind of sample, I find that fifteen-year old children will respond far differently to these questions than a 27-year old who is independent and on his own.
- A: In some of the categories, of course, there were a number of factors that contributed to the variability of the results. Where, for instance, a child was a mother, she seemed to have a more mature attitude toward parenting her own parent. When we questioned one subject further on this, she felt that the time had come prematurely. She had always expected to parent her parent in her parent's old age, but not so soon. She felt her expectations were met a little earlier, and that is how she reconciled herself to the situation. For the 15-year old, she was certainly burdened with many responsibilities she had never considered. These factors did in fact pull the results in polar directions.
- Q: The child who takes responsibilities for his parent is generally one of several children. Usually the one who has those parenting tendencies steps out and takes those responsibilities. I assume your child-subjects were those primary caretakers. Did you question the other children?
- A: This is what I meant by suggesting that emotional proximity as well as the parent-child sex distribution has to be further analyzed. I know that we polled the primary "significant other" in most cases. In other instances, we interviewed the child who was not living at home but who was most available to us, and in whose family constellation the unaffected spouse was assuming more of the responsibility. In our future study we will control the sample for widowed aphasic persons, for example, or only for aphasic persons with single children. These were variables that affected the results.
- Q: Are there similar data concerning children of aging parents in our own literature or in that of other disciplines?
- A: I'm not really sure. Such data may be present in sociological literature.
- Q: It would seem important to run a matched control group. A number of the things you have listed, such as irritability and role-changing, seem to occur as a function of aging.
- A: Except that in normal aging, the transformations of guilt, the transformation of altered social life, and the transformation of the other categories, comes about more gradually. What we tried to look at was how these factors, which might eventually have been met over time, occur abruptly, subsequent to the trauma of stroke.
- Q: I think both the question and the rebuttal are well-taken. An alternative measure would be to compare your sample with that of another acute-onset disability. Amputee populations are usually available in rehabilitation settings, for example, where there is a significant alteration in life-style to the extent where it may worsen the dependency on the offspring.
- A: Perhaps. I would really need to spend time deciding what is a comparable disability. I would much rather look at a normal population, as was suggested, but it would take some effort to match such a sample.

- Q: How would you feel about right CVAs with hemiplegia and no aphasia?
A: That seems comparable.
- Q: I'm curious as to which responses indicate a counseling need as opposed to your offering a simple statement of fact concerning some attitude the children had towards their parents' disabilities.
A: We asked them directly if they considered seeking counseling and if they did in fact receive counseling.
- Q: You concluded that the children of aphasic persons have counseling needs. Can you specify what you think they are? Have you uncovered some problems that could be helped with counseling as opposed to just an attitude they have that doesn't need counseling?
A: Where it seems to reflect, for instance, that they are infantilizing their parent and are unaware of it and think their behavior is appropriate, I think this is an immediate invitation for us to do some counseling, because it affects their communicative style. Where it appears that they're not letting their parent talk at all, or are avoiding communication with their parent because it's difficult to understand them or because they can't express themselves well, I think this is another indication for us to intervene.
- Q: You found several children who were anxious about their new responsibilities. Did you find any children who evidenced the opposite; that is, who seemed to shirk the problems of having an aphasic parent?
A: One respondent I interviewed grossly denied any problems at all. This particular respondent had a lot to learn, I felt, and at this point, 6 months later, is finally awakening to how heavy those responsibilities are. In fact, her parent was the most severely affected of the aphasic subjects.
- Q: Can you speak to the reliability of the questionnaire's results?
A: The four of us sat down and administered the test to the aphasic patients, and then we interviewed the children. Then, for any ambiguous responses, we re-played the tapes to decide what the response was. Generally we didn't have that problem because the child checked off the appropriate answer.
- Q: Yes, but how about the reliability of their answers?
A: We didn't administer it in its entirety and then go back a few weeks later.
- Q: Did you check to see if your results were affected by recent problems in the family other than stroke? For instance, a financial or other sort of problem?
A: We would have to control not only for factors such as those you cited but for premorbid expectations of the child, as well as the prior child-parent emotional proximity. Although this study is preliminary, we do hope to continue our research towards bettering the quality of the therapeutic relationship between the aphasiologist and the family of the aphasic person.

APPENDIX A

NON-LINGUISTIC APHASIA ANALYSIS FOR CHILDREN OF APHASIC PERSONS

1. Since the stroke I find that I play the role of parent.
___almost always ___usually ___sometimes ___rarely ___almost never
2. I feel that I bear a greater share of the responsibility than my other siblings.
___almost always ___usually ___sometimes ___rarely ___almost never
3. I now find that I have the responsibility of making financial decisions.
___almost always ___usually ___sometimes ___rarely ___almost never
4. I now find that I am responsible for household chores.
___almost always ___usually ___sometimes ___rarely ___almost never
5. I now find that I am responsible for planning my parent's social activities.
___almost always ___usually ___sometimes ___rarely ___almost never
6. Since the stroke, my parent needs my guidance in making medical decisions.
___almost always ___usually ___sometimes ___rarely ___almost never
7. Since the stroke my parent needs my guidance in taking care of younger siblings.
___almost always ___usually ___sometimes ___rarely ___almost never
8. Since the stroke my parent needs my guidance in his/her personal care.
___almost always ___usually ___sometimes ___rarely ___almost never
9. Since the stroke I find that I lose patience with my parent.
___almost always ___usually ___sometimes ___rarely ___almost never
10. I find that making visits to my parent provokes anxiety.
___almost always ___usually ___sometimes ___rarely ___almost never
11. After I spend time with my parent I feel irritable.
___almost always ___usually ___sometimes ___rarely ___almost never
12. Rank the following situations according to the degree to which they make you feel irritable. (1 is most irritable, 6 is least irritable)
___making financial decisions for my parent
___assuming responsibility for household chores
___planning for my parent's social activities
___taking care of my younger siblings
___making medical decisions for my parents
___assuming responsibility for my parent's personal care

13. Rank order in which you feel these factors contributed to your parent's stroke. (1 is contributed a great deal, 8 is contributed very little)
- occupation
 - household responsibilities
 - relationship with spouse
 - financial obligations
 - general health
 - relationship with children
 - relationship with others
 - self-imposed stress
14. Since the stroke, I interact (visit, have dinner, etc.) with my parent (too much) _____ (not at all)
15. Since my parent's stroke, my social life has changed (considerably) _____ (not at all)
16. The care of my parent takes time away from my own social activities.
 almost always usually sometimes rarely almost never
17. Since the stroke my parent expects me to spend time with him/her.
 almost always usually sometimes rarely almost never
18. Since the stroke, I actually spend time at home
 almost always usually sometimes rarely almost never
19. My personal conversations with the family are occupied with discussion of my parent's problem and/or with my difficulty in handling it.
 almost always usually sometimes rarely almost never
20. Reactions of other members of my family to conversations about my parent can be described as interested tolerant annoyed
21. My personal reactions outside the family are occupied with discussion of my parent's problem and/or with my difficulty in handling it.
 almost always usually sometimes rarely almost never
22. My friends' reactions to conversations about my parent's problem can be described as interested tolerant annoyed
23. Rank the order in which you rely on individuals for emotional support in handling your parent's problem (1 is most, 9 is least)
- friends clergyman spouse physician other parent
 - psychotherapist speech pathologist self other professional
- (specify) _____
24. Since the stroke, friends who typically visited me at my parent's home are still likely to visit
 almost always usually sometimes rarely almost never
25. Since the stroke I am likely to involve my parent in a social situation.
 almost always usually sometimes rarely almost never

26. Since the stroke I assume financial responsibility for my parent's care.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
27. Rate the extent to which the financial status of the family has been altered by your parent's medical and/or rehabilitation expenses
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
28. The medical and/or rehabilitation expenses for my parent are/have been reimbursed by one or more health insurance plans.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
29. The medical and/or rehabilitation expenses for my parent make it necessary for me to curtail other activities.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
30. Medical and/or rehabilitation expenses make it necessary for me to seek additional income
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
31. The financial responsibility for my parent is shared by _____
-
32. As a result of the stroke, did your unaffected parent seek additional income? If so, how? _____
33. Since my parent's stroke, I find it difficult to concentrate on my school and/or professional work.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
34. I take time off from my job and/or school to directly care for my parent
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
35. My performance in school and/or at work suffers because of my concern over my parent
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
36. My instructors and/or employer complain about my performance.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
37. My professional and/or educational decisions are influenced by considerations about my parent's future
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
38. My physical health is affected by the strain of my parent's illness.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
39. My emotional health is affected by the strain of my parent's illness.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never
40. I am considering seeking professional counseling and/or psychotherapy to help me deal with the strain of my parent's illness.
 ___ almost always ___ usually ___ sometimes ___ rarely ___ almost never

41. I have had to seek out professional counseling and/or psychotherapy to help me deal with the strain of my parent's illness.
 almost always usually sometimes rarely almost never
42. Since the stroke I find that I am protective of my aphasic parent.
 almost always usually sometimes rarely almost never
43. I find that I try to ignore the problem and treat my aphasic parent as usual
 almost always usually sometimes rarely almost never
44. I find that I am tolerant of the problem and treat my aphasic parent as usual
 almost always usually sometimes rarely almost never
45. Since the stroke I find that I am protective of my non-aphasic parent
 almost always usually sometimes rarely almost never
46. I feel that I have a greater share of the responsibility than my non-aphasic parent
 almost always usually sometimes rarely almost never
47. I feel that I am neglected by my non-aphasic parent because of his/her pre-occupation with my aphasic parent
 almost always usually sometimes rarely almost never
48. Do you ever discuss the language impairment with your aphasic parent?
 almost always usually sometimes rarely almost never
49. Do you ever discuss the stroke problem with family-members of other stroke people?
 almost always usually sometimes rarely almost never
50. If given the opportunity would you find it helpful to discuss your parent's problems with family-members of other stroke-people?
 yes no