

Long-Term Survival Characteristics
In Stroke Induced Aphasia

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There are data available (NINCDS National Survey of Stroke, 1981) describing the immediate and long-term survival characteristics of the general stroke population. However, little information is available to describe the special segment of this population of greatest interest to speech/language pathologists, namely, survivors of stroke who are rendered aphasic and who are subsequently seen for aphasia treatment. This study addresses long-term morbidity and mortality in such a sample. The rationale for the study is that those who treat aphasic patients should have a basis for evaluating their work in its long-term context. The central question investigated here is simply, what happens over time to treated aphasic patients?

METHOD

Telephone interviews were conducted to obtain information regarding morbidity and mortality of 92 reachable subjects from studies which originally validated and normed the test of Communicative Abilities of Daily Living (CADL) (Holland, 1980). Fifty-nine males and thirty-three females comprise the sample of the present investigation. Eighty-five were right-handed, 4 left-handed and 3 were ambidextrous. Eighty-five were white and 7 were black. The mean age at onset of aphasia was 56.9. All original CADL subjects whose aphasia was engendered by causes other than cerebral vascular disease confined to the left cerebral hemisphere were excluded. The spouse or another family member served as informant for subjects who were living at home, while in the case of institutionalized subjects, the primary care nurse served as informant. For subjects who died prior to the interview date, information was obtained from medical records. Aphasia type and initial severity were obtained for all subjects from the CADL files (Table 1). For all living subjects, respondents provided information with regard to the following variables: 1) age at interview, 2) years post onset (YPO) at interview, 3) length of speech and language therapy received, 4) occurrence of additional strokes, 5) presence of co-occurring medical problems, 6) the subject's level of functional daily activity, and 7) frequency of regular medical follow-up. For deceased subjects, age at death, YPO at death, and cause of death were obtained.

Table 1. Aphasia type and severity (BDAE).

TYPE	SEVERITY (BDAE)
Broca - 36	0 - 3
Wernicke - 14	1 - 24
Conduction - 2	2 - 23
Anomic - 7	3 - 13
Mixed - 19	4 - 16
Trans. Sen. - 1	5 - 13
Global - 13	

Frequency counts were obtained for discrete variables. Measures of central tendency and variation were computed for continuous data. Deceased and living subjects were compared for age at onset of aphasia, YPO at interview vs. death, and age at interview vs. death, using t-tests for independent samples. Chi-square tests were applied to investigate other possible differences between living and deceased subjects. These included the variables of aphasia type, initial severity and gender.

RESULTS

Forty percent (37 subjects) of the cases surveyed had died prior to our follow-up. This group was characterized by a mean age at stroke of 62.4 years, mean YPO at death of 5.1, and a mean age at death of 67.5 years. Seventeen of these subjects died from some form of coronary disease, 12 subjects died from a second stroke, 4 died from unrelated conditions and the cause of death for the remaining four subjects could not be determined.

Sixty percent (55 subjects) were living at the time of interview. Of these, 12 were institutionalized. The survivors had a mean age at stroke of 53.2 years, a mean YPO at interview of 8.9 and a mean age at interview of 62.0 years. Comparing mean age at onset between the two groups, we found survivors to be significantly younger at onset than their deceased counterparts ($t = -3.97$; $df = 90$ $p < .01$). The comparisons between mean YPO at death vs. interview ($t = 4.55$; $df = 90$ $p < .01$), and mean age at death vs. interview ($t = 2.46$; $df = 90$ $p < .01$) likewise yielded statistically significant results. These results suggest that age at the time of stroke had a marked effect on the likelihood of long-term survival. It occurred to us that these findings might simply mean the older, nonsurviving group had reached their statistical life expectancy. However, because there was a considerably large range in the distribution of age at the time of death we decided to look at individual cases. This analysis revealed that 59 percent of the deceased subjects were 65 years of age or younger when they died. What distinguished this group from survivors was the co-existence of multiple medical problems including diabetes, heart disease, pulmonary dysfunction and hypertension. Long-term survival, therefore, did not appear to be solely attributable to age at the time of stroke.

We also compared the variables of aphasia type, initial severity and gender between groups. A significant chi-square was obtained only for aphasia type ($X^2 = 7.43$; $df = 3$ $p < .05$). This finding is potentially confounded by the significant differences between the mean ages of the surviving and nonsurviving groups. Several studies relating age to type of aphasia have found that Wernicke and Global patients are older than the mean for the aphasic population, and others have suggested that Broca's aphasic patients are younger than the mean (cf. Obler, Albert, Goodglass, and Benson, 1978; Holland and Bartlett, 1984).

Because a large percentage of our subjects are long-term survivors, variables that might help to describe their survival experience were investigated. For example, family members reported on the duration of speech pathology services. These data revealed that survivors received a mean length of four and one half years of speech pathology services. We did not attempt to obtain information regarding either the nature or the frequency of contact. However, environmental factors and patient variables that may have been contributory in this regard were investigated. Forty-three subjects from the surviving group were analyzed. Twenty-four of these subjects received speech and language services from the Veterans Administration and the remaining 19

subjects received services from private hospitals or clinics. Within the veterans group, 63 percent of the subjects had some form of contact with the speech pathologist for more than 4 years. Only 32 percent of those individuals receiving services from the private sector were followed for the same length of time. This suggests that cost and availability of services have some influence on the duration of services received. When we looked at the initial severity ratings of the 21 subjects from both groups who received more than 4 years of speech pathology services, we found the majority to be within the moderate to severe range. Interestingly, however, our conversations with the family members of these subjects suggested that while language problems persisted, the sessions with the speech and language pathologist provided a valued and much desired opportunity for social and communicative interaction in an otherwise socially isolated group.

Subjects' level of functional daily activity was also investigated. To capture this, a 5-point rating scale was developed (Table 2). Ratings were assigned taking into consideration premorbid level of functioning. For example, a homemaker who returned to her premorbid level of maintaining her home was assigned a 5- "return to premorbid employment/activity." An individual previously employed outside the home who was subsequently able to perform only household activities received a rating of 2- "limited activity." Institutionalized subjects received a rating of minimal or limited activity depending upon what activities they performed beyond their self-care. Of the 48 cases responding, 32 received a rating of minimal or limited activity, 10 received a rating of normal activity and 6 returned to their premorbid level of functioning. It should be mentioned that the 7 missing cases were all institutionalized; therefore, only 5 subjects receiving minimal or limited activity ratings were institutionalized. Thus, 62 percent (27/43 subjects) of non-institutionalized survivors in our sample were essentially homebound. These findings provide further evidence of the limited social contexts in which subjects had opportunities to engage in some form of social and communicative interaction

Table 2. Ratings of functional daily activity.

1. MINIMAL ACTIVITY	Needs assistance with self-care or self-care with no additional activity, (i.e.) watches TV only.
2. LIMITED ACTIVITY	Self-care plus other productive activity limited to residence, (i.e.) gardening, household work, sewing, non-prescribed therapies.
3. NORMAL ACTIVITY	Self-care plus activities outside of residence requiring social interaction, (i.e.) driving, shopping, stroke clubs, card clubs, local entertainment.
4. VOLUNTEER WORK	Regular volunteer work outside of residence.
5. RETURN TO PREMORBID EMPLOYMENT OR ACTIVITY	

We also investigated the incidence of co-occurring medical problems, additional strokes and frequency of medical follow-up. Seven members of our sample survived an additional stroke. If we consider those 12 subjects who died as a result of their second stroke, then 21% of the original sample suffered an additional stroke. This finding is particularly important when

one considers that this represents a 63% mortality rate for those individuals sampled who suffered a second stroke. All but four subjects continued to receive regular medical follow-up with hypertension, heart disease, seizure disorder and diabetes being the most commonly reported associated health problems.

CONCLUSIONS

In summary, these data are consistent with the more general stroke statistics, at least as far as mortality, second stroke, and associated medical problems are concerned. This suggests that the presence of a language disorder does not contribute disproportionately either to higher or lower survival factors, and that the general stroke statistics are appropriate sources for prognosticating about these variables in this unique subset of stroke patients.

For survivors, the long-term quality of life issues minimally addressed here appear to be relatively bleak and in need of further explication and study. The duration of speech and language pathology services rendered is an interesting example. On the one hand it could be argued that it results in a very unfavorable cost-benefit ratio. On the other hand, the reported psychosocial benefits described by the family members of these patients have implications for the role of the speech and language pathologist in managing chronic aphasic individuals and their families. A basic question is whether the obvious humanistic value of therapy warrants the continued provision of services for patients who have reached their maximum level of functional improvement. If so, then what should the nature of our involvement be? Wertz (1981) has stated that treatment must go beyond improving the aphasic patient's communicative abilities. Because complete recovery from aphasia is rare, he urges clinicians "to be ready to intervene with treatment that assists their patients in living with aphasia's residuals." For many, a critical factor is the continued opportunity for social contact in an environment where communication is encouraged, facilitated and reinforced. When such opportunities are not available to the chronic aphasic patient outside of our clinics, we are likely to continue to provide them within our clinics. We recommend a fuller utilization of volunteer schemes to meet the basic socio-communicative needs of the chronic aphasic patient.

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DISCUSSION

- Q: Were the subjects who were in therapy four years post-stroke receiving group or individual treatment?
- A: We have no data regarding the nature of therapy. On our questionnaire we only investigated the duration of contact with speech pathology services.
- Q: With all of the talk about DRG's, these data don't speak too well for what we're doing, at least from the viewpoint of people outside of our field, and yet in your presentation you made some very strong points about some of the positive things that our services are providing for aphasic patients. Would you comment on how we can use your data to demonstrate that speech pathology services beyond a certain point are needed and are cost effective?
- A: I'm not sure that my data can demonstrate the cost effectiveness of therapy over such a long time and this is one of the reasons why we recommend fuller utilization of volunteer programs.
- Q: Do you think the data you presented can assist us in making discharge decisions for patients who may not be progressing in therapy?
- A: No, I do not think these data can assist a clinician in making discharge decisions. What we are trying to suggest is that at some point in the management of our patients, we should consider utilizing volunteer schemes to meet the basic socio-communicative desires and needs of our patients.
- Q: Do you have a sense that those patients who did not return to their pre-morbid level of functioning were leading unfulfilled lives? I don't believe that we expect these patients to return to previous levels of functioning.
- A: There was an approximately equal distribution of reports that indicated poor and good overall adjustment. What we felt was significant was that the positive comments generally came from those families who had maintained longer contact with their speech therapist and/or clinic.
- Q: What constituted the treatment you are reporting on? There are some medical centers, the Veterans Administration being some of these, that have rules that say you cannot treat a non-service-connected outpatient for more than one year. My question is, do you feel that your data, the way you're reporting them could be at all dangerous without describing the kinds of therapy that actually went on?
- A: Your comment is well taken. As I mentioned previously, this study is limited in that we did not obtain information regarding either the nature or the frequency of therapy. The item on our questionnaire regarding the duration of therapy was only one of several questions, the purpose of which was to obtain a general picture of the survival experiences of chronic aphasic individuals. It was not the purpose of this investigation to address the issue of the efficacy of language rehabilitation and to interpret our results in such a manner would be erroneous.
- Q: Is it possible that your question on duration of services could have been misinterpreted by family members? Many patients receive therapy for a few months, are discharged and then return some time later. If you did

not ask your question in such a way to get at this, then I think you could have a major problem with your data.

Q: Do you think the family member could distinguish between treatment and participation in a research project?

A: We did not attempt to obtain information regarding the nature of the contact between subjects and their therapists. At least five of the subjects were from our clinic and three of those were in group therapy, only one was in individual therapy, and one had come back for a six week contract. So, I do think this is not all just individual therapy.