

## Relatives and Aphasia Clinicians - Do They Agree?

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Aphasia clinicians have recognized that the family's perception of the patient's ability to communicate is an important issue in counseling (Helmick, Watamori and Palmer, 1976; Linebaugh and Young-Charles, 1978; Flowers, Beukelman, Bottorf and Kelley, 1979; Shewan and Cameron, 1984). Several investigators have compared the perceptions of family members with those of aphasia clinicians. Flowers, *et al.* studied family members' perceptions of how their aphasic relatives would perform on seven language tasks, including "activities of daily use." These investigators found that only 29 percent of the family's predictions were incorrect (did not agree with scores assigned by clinicians). When relatives erred in their predictions, they tended to overestimate aphasic performance. Helmick *et al.*, examined ratings of communicative ability by family members on the Functional Communication Profile (Taylor, 1965), and compared them with ratings by clinicians. A significant difference was found between ratings made by the two groups of respondents. Family members tended to assign higher ratings than did clinicians.

A recently completed Veterans' Administration cooperative study (Wertz *et al.*, 1983) provided the opportunity to compare the amount of agreement between family members and experienced aphasia clinicians who rated aphasic patients' ability to perform communicative activities of daily living. Although not a primary purpose of the V.A. investigation, within the design of the cooperative study it was possible to examine the amount of agreement over time and to study the effects of treatment on the ratings.

### METHOD

#### Participants

Aphasic subjects were ten male outpatients between the ages of 45 and 75 years. All had sustained a first left hemisphere thromboembolic CVA between two and 24 weeks prior to participating. Education level for these subjects ranged from 8th grade to graduate school. Overall percentiles on the Porch Index of Communicative Ability (PICA) (Porch, 1967) ranged from 10-80. All patients were subjects in V.A. Cooperative Study #110. No aphasic subject had received treatment for his aphasia prior to participation in the present study.

Ten family representatives (hereafter referred to as relatives), one per subject, participated. All relatives reported occupying the same dwelling as their aphasic family member.

Two aphasia clinicians were participants. Both were trained in the administration of Communicative Abilities in Daily Living (CADL) (Holland, 1980).

#### CADL Test and Interview

The CADL test uses communicative adequacy as the standard for measurement. The scoring system is a three point scale; 0, 1, or 2. A score of 2 is assigned if the patient's message is understood by the examiner; a 1 response

is a rating somewhere between "message conveyed and message not conveyed." A clearly inadequate response is scored 0.

The CADL interview contains items designed to provide a rating of the aphasic patient's functional communicative ability. There are two sets of questions, the second of which is rated on a three-point scale. An informant, in this case, the relative, assigns a score of 2 if he believes that the patient never needs help, a score of 1 to indicate that the aphasic patient sometimes needs help, and a score of 0 if he believes that the patient always needs help. Thus, the rating scale used for this set of questions in the CADL interview is comparable to the scale used in the CADL test.

#### Procedures

CADL was administered by an aphasia clinician to each subject on three different occasions over a period of 12 weeks. A baseline measure was obtained for each patient at 2 - 24 weeks postonset of aphasia. A second administration of the test occurred six weeks after the baseline examination, and a third administration at 12 weeks following the baseline testing. Thus, there were baseline, six, and 12 week measures for the CADL test for each aphasic subject.

CADL interview items were rated by relatives immediately after the administration of the CADL test; therefore there were baseline, six and 12 week measures for the interviews as well as for the tests. Following the baseline test and interview, one-half of the aphasic subjects began treatment; the remaining subjects had no treatment during the 12 weeks of the study. Thus, it was possible to compare the difference between the ratings by relatives and clinicians over time and to determine whether the ratings were influenced by treatment.

#### Data Analysis

Twenty-five interview items were paired with test items. For example, the interview item, Getting Assistance from a store clerk was paired with the test item in which the examiner says:

"You need shoelaces. A clerk says, 'May I help you.'  
What do you say?"

Ratings for relatives and clinicians were tabulated for the 25 pairs of items for the treated and untreated subject groups. Ratings were tabulated for the baseline, six and 12 week measures. The number of pairs on which ratings were identical (agreement) was calculated for each subject group and for each measure. The number of pairs on which relatives assigned higher ratings than clinicians did was totaled for each group, for each measure. The number of pairs on which clinicians assigned higher ratings than relatives did was totaled for each group for each measure.

### RESULTS

Table 1 presents the percentage of agreement between relatives and clinicians for treated and untreated groups and for baseline, six, and 12 week measures. Results of Chi Square analyses indicated that the rate of family-clinician agreement between groups did not differ significantly, ( $X = .27$ ;  $p > .05$ ); that in the treated group the rate of agreement between relatives and clinicians did not change significantly over time ( $X = .16$ ;  $p > .05$ ), and that in the untreated group the rate of agreement did not change significantly with time ( $X = 1.986$ ,  $p > .05$ ).

Table 1. Percentage of agreement for subject groups over time.

|           | Baseline | Six Weeks | Twelve Weeks |
|-----------|----------|-----------|--------------|
| Treated   | 41       | 43        | 41           |
| Untreated | 35       | 35        | 43           |

Chance rate of agreement: 33-1/3%.

Chi Squares were computed to determine whether, in the two subject groups (treated, untreated), the number of higher scores assigned by relatives changed over time. No significant change over time was found for either the treated ( $X = .026$ ;  $p > .05$ ) or the untreated ( $X = .213$ ;  $p > .05$ ) group.

When the total number of items on which higher ratings were assigned by clinicians rather than relatives was submitted to Chi Square analysis, no significant change was found over time for either group; treated ( $X = 4.695$ ;  $p > .05$ ), or untreated ( $X = .50$ ;  $p > .05$ ).

#### DISCUSSION

In the Flowers, *et al.* and the Helmick, *et al.* studies, the amount of agreement between the two groups of respondents was higher than it was in the present study. Likewise, Holland (1980) in her study of noninstitutionalized patients, reported greater agreement between interview and test items than was found for the participants in the present study. The discrepancy between the findings of previous studies and the results of the present investigation may be related to time postonset of aphasia. Flowers, *et al.* reported that post-onset time ranged from three months to 13.8 years and Helmick *et al.* reported a postonset time ranging from 2 to 12 months. For the patients in Holland's study, postonset time ranged from 3 to 86 months. Time postonset in the present study was 2 to 24 weeks. Relatives may have had less experience with aphasia than the participants in the previous investigations did, and therefore, may have had fewer observations on which to base their ratings.

The amount of family-clinician agreement between subject groups did not differ significantly. Neither did the number of higher family ratings between groups nor the number of higher clinician ratings between groups differ significantly. These findings suggest that ratings of neither relatives nor clinicians were influenced by whether or not the subjects were receiving treatment.

In order to determine whether the rate of agreement would change when relatives provided the aphasia therapy, four relatives of aphasic patients (one daughter and three wives) were taught how to conduct aphasia therapy with their aphasic family member. Treatment sessions were conducted in the patients' homes and, once every two weeks, relatives and aphasic patients would return to the clinic, where they were observed during a treatment session. Thus, treatment was monitored closely. CADL test results and interviews were obtained at baseline, six and 12 weeks.

Table 2 shows the percentage of agreement for the three subject groups over time. As can be seen in Table 2, the rate of agreement for the family-treated group increased at the six-week evaluation and continued to rise as shown by the 12-week measure. It appears that when relatives became involved in providing treatment, their perceptions began to change and, over time, more closely approximated those of the aphasia clinicians .

Table 2. Percentage of agreement for subject groups over time (includes family-treated group).

|                   | Baseline | Six Weeks | Twelve Weeks |
|-------------------|----------|-----------|--------------|
| Clinician Treated | 41       | 43        | 41           |
| Untreated         | 35       | 35        | 43           |
| Family Treated    | 44       | 53        | 68           |

Chance rate of agreement: 33-1/3%.

### Clinical Implications

The wise clinician knows the error of basing clinical decisions on group data only. It was evident from data for individual subjects that some family members assigned higher ratings to some activities than clinicians did. On the other hand, on some items, higher ratings were assigned by clinicians than by relatives. These findings have implications for counseling families of aphasic patients. Those families assigning higher ratings than CADL test scores would indicate are appropriate could be counseled that their perceptions, and therefore, their expectations for the patient might be unrealistic. Conversely, those families who assign lower ratings than CADL test scores would indicate are appropriate could be counseled that their expectations are not high enough -- that their aphasic relative is capable of performing certain communicative activities of daily living more effectively than the relative's rating suggests. From the results of this study, it seems likely that CADL test and interview could be used in combination as a basis for counseling the families of aphasic patients and that the rate of agreement between relative and clinician could improve after counseling.

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