

## AN INNOVATIVE THERAPEUTIC PROGRAM FOR APHASIA PATIENTS AND THEIR RELATIVES

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**ABSTRACT.** Eleven aphasia patients and seven family members participated in a five-day residential course led by a speech pathologist, a psychologist and a neurologist. The aim of the course was to give the aphasics and their relatives information on the etiology, treatment possibilities and prognosis of aphasia; work on personal and interpersonal problems through psychological counseling; improve language function through comprehensive and intensive stimulation; examine the psychological, linguistic and neurological effects of the intensive course. The course participants met again one year after the course and were found to have changed positively both psychologically and interpersonally but, as expected, only to a minor degree linguistically and neurologically. Through this intensive course it was possible to assess the problems of the families more easily than in the hospital. The patients and their relatives reported that they had learnt how to identify and to deal with their psychological problems in a more constructive way. They also felt that they had support from the other families and were able to share their experiences. We found that this type of intervention had many positive effects on the ability of the participants to cope with the chronic disability.

*Key words:* aphasia, rehabilitation, family therapy, spouse, psychological and social adjustment, depression

### INTRODUCTION

Few studies have assessed the influence of family members on aphasic stroke patients. The few studies extant show an obvious need for bringing spouses into the rehabilitation process. Malone et al. (6) reported that the attitudes of the families of aphasics were often "unhealthy" because of mistaken beliefs about strokes. They suggested that aphasics and their families would benefit from counseling.

Helmick et al. (5) found that the spouses of aphasic patients viewed the patients' communication ability as less impaired than it actually was. Mulhall (8) reported that the mutual influence aphasic stroke patients and their relatives have on each other, and the emotional behaviour of the spouses—in reaction to the patients' communication disorder—aggravates the verbal output of the patients.

In Sweden, as in most countries, therapy for aphasics is concentrated in larger hospitals in urban areas. In the more remote areas, treatment if any, is mediated by occupational therapists or untrained persons. As a consequence little or no information on aphasia and its concomitant problems is given to aphasic patients and their families. This was the primary impetus for the design and implement of the present study.

The aim of the present study was to examine the psychological, linguistic and neurological effects of an intensive five-day informational and psychotherapeutic regimen given to aphasic patients and their families in a residential situation.

### METHODS

The patients were selected according to the following criteria: they lived in the area (county) where the course was held, they were known to at least one of the four speech teachers who worked in the area, they were able to bring a family member and they were not globally aphasic. From this population the final participants were selected at random.

Eleven aphasics and seven family members attended the five-day intensive course given at a boarding-school in a small town in Sweden 1978.

The course was led by a speech pathologist, a psychologist and a neurologist assisted by four speech teachers (school teachers with one year of postgraduate training in language and speech).

The participants met in four groups, each group led by a speech teacher, in which different activities were given. We tried to make the groups as homogenous as possible. Family members were not grouped together with their aphasic spouses in order to avoid the overprotective attitude so often shown by family members. Group participants discussed the news from the daily papers, objects that the participants had brought with them, music that was played in the groups, poems that someone read to the others, they sang familiar songs etc. In small groups the aphasics practised reading and writing or naming objects.

One family at a time left the group meetings to see the psychologist for examination and family therapy. In the

Table I. Aphasia type and occurrence of depression during the course and at follow-up

Case	Age	Aphasia type		Depression	
		During the course	At follow up	During the course	At follow up
1	40	Anomic	Anomic	No	No
2	41	Mixed non-fluent	Mixed non-fluent	Yes	Improved
3	39	Mixed non-fluent	Mixed non-fluent	Yes	Yes
4	54	Mild Wernicke	Mild Wernicke	No	No
5	62	Anomic	Anomic	No	No
6	47	Anomic?	Anomic	Yes	Yes
7	45	Anomic	Anomic	Yes	No
8	59	Mixed non-fluent	Transcortical motor	Yes	No
9	61	Conduction	Conduction	Yes	Improved
Mean age 50					

neuropsychological examination an interview was performed to assess the neuropsychological deficits. In this interview the spouses were asked to report their observations. The following abilities were explored: (a) memory, (b) concentration, (c) emotional self-regulation, (d) intellect, (e) perception, and (f) abstraction. The psychologist also looked for somatogenically based changes in the patient's behaviour. The test which was administered in intra-individual comparison is the widely used standardized Swedish test-battery, the "Dureman-Sälde battery" (3). Other tests, used in intra-individual examination, were Benton's Revised Visual Retention Test (2) and the Thematic Apperception Test (TAT). Test results were evaluated with great care since the measures were not designed for use with aphasics.

Psychological reactions were identified by an unstructured interview approach and were classified into six groups according to what is in general use by the American Psychiatric Association: (1) anxiety, (2) dissociation, (3) conversion, (4) phobic reactions, (5) obsession, compulsion, and (6) depression. These reactions were described by the patients in the first interview and were reexamined in the follow-up study.

Family therapy was provided by the psychologist. The main technique used was conjoined family therapy (10). This technique focusses upon the relationships in the family rather than upon the personality structure of each member of the family. In the present study the psychologist tried to explore the changes in the relationships that had occurred because of the aphasia. The therapeutic presupposition was that the present situation, i.e. with one aphasic family member, was not only determined by the aphasia but also by the other interpersonal factors that were present before the new situation occurred. It was postulated that the change in the family system caused by the aphasia takes a lot of energy from the family unit. If the family has difficulties to cope with the problems in a constructive way this might increase the problems for all members of the family, e.g. depression, impaired communication and feelings of guilt.

All patients were neurologically examined. The language examination comprised the Gothenburg Aphasia Test (1) combined with items from the Boston Diagnostic Aphasia Examination (4) arriving at a diagnosis of aphasia syn-

dromes based on the classification system used at the Boston Veterans' Administration Hospital.

All participants listened to lectures on the cause, treatment and prognosis of aphasia, and its accompanying neurological deficits. A lecture was also given on the psychological aspects of aphasia.

The social program consisted of an excursion to a city nearby where we visited a museum, an aquarium, a glass-blowing work shop and a restaurant. The aim of the excursion was to provide stimulation in all possible ways. Speech was encouraged, e.g. ordering the meal at the restaurant and asking for the bill. In the evenings the participants discussed and compared their every day problems with the other families and were thus given new ideas how to solve their own difficulties.

The participants filled in a questionnaire in which they gave their opinion of the value of each part of the program. All participants enjoyed the program and denied being disappointed with the outcome of the course.

One year later nine of the aphasics and six of the family members met again for five days for re-evaluation (cf. Table I). Two patients failed to attend, one because of a gall-bladder operation, the other because of a vacation. Again, the same linguistic, neurological and psychological test procedures were performed. A similar questionnaire was filled in during the follow-up period. The questionnaire had cognitive variables, but this time an attitude scale with behavioural aspects of the participants were included.

## PATIENTS AND RESULTS

*Case 1*, a 40-year-old male with a subarachnoid haemorrhage four years previously. He had a persistent slight right-sided hemi-hypesthesia and an anomic aphasia. He attended the course alone. His wife had told us that she needed to rest. The patient reported to the psychologist that he and his wife often quarrelled about the present situation. He claimed that his wife was exaggerating his difficulties. In the psychological examination an almost ob-

sessive denial of the patients aphasic problems was noted.

At follow-up after a year he was still disinclined to accept his aphasia and preferred to talk about his premorbid situation. However, he did not dissociate himself from further conversation with the psychologist anymore. During the period between the course and the follow-up the patient and his wife spontaneously asked for family-therapy at the hospital. This turned out to be a break-through for the patient in understanding his wife's concerns. At follow-up they both described their every day life together as more free from tensions. It is noteworthy that they both decided to attend family therapy after the first course.

*Case 2*, a 41-year-old male with a subarachnoid haemorrhage seven years previously. At the neurological examination during the course he still showed a severe right-sided hemiparesis and hemi-hypesthesia and a mixed non-fluent aphasia. At examination he also showed signs of a deep depression which in part might be due to the fact that his wife had divorced him just after he left the hospital. Together with the psychologist the patient was given the opportunity to act out his feelings against his former wife.

At follow-up after a year his depression, although still present, did not prevent him from adapting to his situation as much as it did in the previous year, and he was noticeably more active. His strong feelings about his former wife were still present but he was not so obsessed by them. A great deal of the time with the psychologist was used for role playing in order to encourage new contacts with women.

*Case 3*, a 39-year-old male with a left-sided cerebral infarction due to an internal carotid artery occlusion one year previously. He had a severe right-sided hemiparesis and a slightly impaired sensation on the right half of the body. He had a mixed non-fluent aphasia, a slight memory defect and a depression.

The family situation for the patient was drastically changed by the disease since he was young and in the middle of his career. All family members were not attending the course but the psychologist worked with the patient and his wife both during and after the course. The main line followed was to work with their mutual disappointment and anger.

At follow-up the patient's depression and disappointment still prevented him from accepting his handicap. The rest of the family was also depressed

and under tension. No improvement was noticed in the family situation.

*Case 4*, a 54-year-old male with a persistent mild Wernicke's aphasia since two years but no hemisymptoms two years after a skull trauma and subdural hematoma. During the one week course the patient had difficulties following conversation. He had also memory and concentration defects. The patient had interpersonal psychological problems, difficulties in keeping an adequate distance to the examiner, and his performance was marked by rigidity in shifting from subject to subject and task to task. He appeared uneasy and had motor hyperactivity. His family reported that they felt tired and overburdened.

At follow-up a year later he was more coherent in his thoughts and could keep an adequate distance to other people more easily. Still his rigidity in shifting from task to task was marked. He was no longer so anxious but still showed psychomotor hyperactivity. Both his wife and his son reported great relief in meeting not only the psychologist but also other people who were in a similar situation. They both reported an improvement in mood. Relations within the family were improved and the wife was positive towards family therapy sessions.

*Case 5*, a 62-year-old male with a probable cerebral infarction one year previously. No hemisymptomatology was found but he had an anomic aphasia. He showed no neuropsychological abnormalities but some psychomotor discomfort. He and his wife supported each other. They both described their relationship as harmonic.

At follow-up after a year a slight improvement of his probably pure anomic aphasia was noted. No changes in the family situation was seen.

*Case 6*, a 47-year-old female with, a probably embolic, cerebral infarction one year previously. The neurological examination revealed a right-sided hemi-hypesthesia and a bilateral general apraxia. She had a possible anomic aphasia although her auditory comprehension was not intact. Neuropsychological tests showed a reduced memory. She was withdrawn, shy and slightly depressed. Her husband reported difficulties in reaching her. He had difficulties in understanding the present situation both intellectually and emotionally, while their son seemed to be more flexible. The adults were stimulated to communicate and to look at each other while they were trying to express their feelings about the situation.

After a year the neurological and the psychologi-

cal findings were unchanged but the aphasia had evolved into a more typical anomic aphasia. An obvious improvement in the relationship between the two adults was seen. They were more at ease in their behaviour and they both reported that they had learned how to cope with their situation.

*Case 7*, a 45-year-old female with a subarachnoid haemorrhage one year previously. The neurological examination showed a slight right-sided hemi-hypesthesia and hemi-dysopia. She had a slight memory defect and she was depressed. She had an anomic aphasia. During the family therapy sessions she was very quiet. Her husband who was a farmer did most of the talking and he assured that this had been the situation even before his wife became aphasic. They both seemed to agree that their main problem was not concerning the patient but their 10-year-old son who had difficulties in school. The counseling was concentrated toward the family system as a whole and the son attended all the sessions.

At follow-up after a year the patient appeared happier and her husband thought that her mood had returned to normal. The family as a whole seemed to function normally now, despite the mainly unchanged situation for their son.

*Case 8*, a 59-year-old male who suffered from an intracerebral haemorrhage in the left temporal lobe two and a half years previously. The neurological examination revealed a severe right-sided hemiparesis and a slight hemi-hypesthesia. His aphasia was mixed non-fluent. The neuropsychological examination showed a partly somatogenously generated asteno-emotional syndrome. He was cerebrotaneous (socially restrained) and emotionally conative (impaired motivation). Psychologically a neurasthenia was noted. His wife complained of the lack of emotional contact in their marriage.

At follow-up after a year he was still cerebrotaneous but markedly less astenic and more emotionally conative. His appearance showed more mobile features. Psychologically he was low-voiced but had ceased to show signs of neurasthenia. He was also more hopeful than at the examination one year previously. His wife was still asking for more emotional contact in the marriage but she said that she knew how and when she could ask for it. She also declared that she understood what was connected to her husband's brain damage and what she could respond to in a more demanding manner.

*Case 9*, a 61-year-old male with a probable left hemisphere infarction. Neurologically and neuro-

psychologically no abnormalities were found. He had a conduction aphasia. His stroke occurred 6 months prior to the course. He seemed to be locked in a reactive depression. He wanted to give up his work and was gloomy about the future. His wife was openly depressed. The depth of the depression and the family situation asked for more radical treatment than plain counseling. A psychodrama technique was used. The situation when the patient became aphasic was role played and they were both given opportunities to react emotionally to the ongoing play. This was done with great care and a lot of support was given to both of them. The psychodrama was emotionally strong and they both cried a lot. They reported great relief after the drama was finished.

At follow-up after a year the patient was less depressed. He remained at his work and had a more realistic view of life. Both the patient and his wife described an improvement in mood. They claimed that their relationship in certain aspects was even better than before the patient became aphasic. Of course the handicap was still there and they were still depressed about it but differently. Or, as they put it, "in an angry and maybe more constructive way".

The questionnaires showed that the participants appreciated both the length and the content of the course. They stated that their knowledge of aphasia was very poor before the first course but good or very good after the course. They experienced that the course had a positive effect on their life situation.

We noted changes in several cognitive and behavioural aspects. The participants reported that they were more informed about aphasia and related neurological, neuropsychological and psychological symptoms. Furthermore, they reported qualitative and quantitative improvement in life situation when compared with before the course. This was found at the follow-up one year after the initial course.

The statements in the questionnaires suggested that a course of this kind, where aphasics and their families have the opportunity to be together under guidance of skilled personnel, is of great value as a complement to traditional aphasia management.

## DISCUSSION

The experience of focussing intensively, in a residential situation, on problems associated with persistent aphasia was unique, in that material which is traditionally spread across the recovery period was tele-

scoped into a short time span at a later point in the recovery course. We felt that the participants had opportunity to assimilate information given in a better way than during the acute state at the hospital. It was also possible for us to give information repeatedly during the five days.

In this single group outcome study, we tried to show how the participants changed over time. No control group was therefore included. A control group would have required a much larger group of participants in order to obtain statistically significant results. This would be insuperable from both a professional and an economical viewpoint.

Most patients seen at rehabilitation clinics show evidence of a better adjustment to their disabilities with time. This is however not always the case. In this study we found an improvement in patients who differed markedly from each other in years post stroke. We therefore suggest that our program per se had a positive effect on the psychological and social qualities of life for these patients. We feel convinced of this since, even if improvement in neurological and linguistic status was found mostly in patients with a relatively short anamnesis, improvement of depression and other psychological reactions were seen also in patients with a long anamnesis.

It seems that the participants and especially the family members appreciated the information on aphasia given to them. Family therapy was of greater concern to the participants than was speech therapy.

While exploring the situation with the family members it became clear to the participants in what ways the aphasia interferes with their lives. Patterns that existed before the aphasia, e.g. the "power-balance" or the sharing of responsibilities within the family, could be seen in a new light and dealt with in new ways.

Through this process the families were given opportunities to verbalize experiences, feelings and thoughts to each other, including "hard" or forbidden feelings. The psychologist provided a permissive atmosphere, gave the family support, and also helped the family members to respond and take initiatives. This was done by letting them become sensitive to the non-verbal signs of the aphasic member and also by letting the sessions take time and allowing all possible forms of communication.

From a therapeutic point of view, the benefits to family members consisted of freedom to share their frustrations with each other, and the opportunity to react freely. Through this therapeutic process the

family could deal more effectively with the new situation.

Many speech pathologists have stressed the importance of giving the family members of aphasic patients the possibility to participate in the rehabilitation process (9). Since most of the participants in the present course thought that the information given was positive, one might conclude that there should be fewer misconceptions within the families.

Our presuppositions about the context most suitable for assimilating the information seemed to be correct since the atmosphere was very relaxed and undramatic. The ongoing dialogue during the course between the hospital staff and the families gave opportunities to work through difficulties that are usually left for families to solve on their own, often with undesirable results. Our experience suggests that the method described seems to increase the potential of the aphasic person and his family to enjoy a more positive and effective rehabilitation and a better adjustment to his disabilities.

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