

A Unique Method For The Follow-up Of Aphasic Patients

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The literature speaks to the need for follow-up studies by rehabilitation programs in order to assess their lasting value. We in the Speech Pathology Department at the Massachusetts Rehabilitation Hospital wished to learn about the lasting effect of our program. To accomplish this, we designed a unique method for the follow-up of aphasic patients-- an "Alumni Reunion." This method allows the discharged patient to remain outside the medical model, not to become the patient again. The massive accounting network is kept inactive and no financial burden is created for the patient and his family.

Our department focuses on fostering independence and encouraging adaptation to new life situations. Our system has been designed to produce graduates! To require the alumni to again become a test-taking patient is in opposition to our philosophy. In keeping with this concept and still permitting follow-up to take place, an "Alumni Reunion" was created. We felt that the reunion offered three advantages: (1) It avoided placing the patient and his family in the traditional patient-therapist model. (2) It provided the opportunity for our staff to engage and observe functional communication skills. (3) It allowed us to probe for the alumni and family's acceptance of changes in life style.

To date four alumni reunions have been held. These Saturday afternoon programs have been divided into three distinct segments, "the reception;" "the shared experience," "the psycho-social focus." The reunion begins with the "reception." It is at this time, over refreshments, that the individual speech pathologists make contact with alumni and families with two purposes in mind; (1) To socially greet them and to learn of their ongoing adjustment and progress since last seen. (2) To probe and assess the alumni's pragmatic communication skills, because we wanted to know how effectively they communicated. That is, we observe whether they initiate speech, generate questions, transmit complete ideas, use appropriate syntactical structures, beneficially use their listener for assistance, withdraw from communicating, and upon whom they place the burden of communication. To code this information, the speech pathologists assign a value from the severity rating scale of The Boston Diagnostic Aphasia Examination. Thus we are able to compare the individual's communication skills from discharge to reunion and at subsequent reunions.

The second portion of the reunion format is the "shared experience." Family members and alumni are brought together into one large group in order to be welcomed and to review the purposes of reunions. Information from a guest speaker about topics of particular interest to post-stroke

patients is presented. The goal of this portion of the program is to provide an opportunity for non-demand listening and to stimulate feelings of cohesiveness.

The third portion of the reunion, the "psycho-social focus" has undergone many changes and just recently has evolved into a plan that seems to work well. Here is a brief review of the stages of development that it has gone through. Initially, during this portion of the reunion, we met with alumni and family members in small groups to discuss issues pertaining to their home and community. The family members communicated the strong need for an opportunity to speak more openly with our staff. Therefore, at the subsequent reunion, separate family and alumni groups were run simultaneously.

During our first family group the space was created for the families to speak more openly of their difficulties in living with an aphasic person. They spoke of the isolation of the family with an aphasic member. This isolation appeared to stem from the alumni's chosen withdrawal, the families decision not to pursue social contact, and/or the rejection of the alumni and family by their former friends. They revealed qualitative differences in their adjustment to home and role changes. The group atmosphere became empathetic and the families requested that at the next reunion they once again have an opportunity to speak freely. We recognized the importance of what had transpired. For the next reunion we looked to someone trained in psychotherapy to assist the family group in moving from mere ventilation to clarification of their feelings. At subsequent family group meetings we've been fortunate enough to progress from the cathartic experience to a supportive group. Our families report that the experience of the group is very meaningful for them and to quote one of our families--"it gives us hope."

The issues of concern to the alumni were less homogenous than those of the families. Our alumni population divided itself into three natural subdivisions. One group was composed of all females with BDAE severity ratings of from 3 to 5. These women quickly assumed a large portion of the responsibility for discussion. With guidance from the speech pathologists, these alumni shared their successes and failures in their role changes, their socialization outside the home and the special efforts they've made to make their lives work again. During this discussion we were privileged to observe peer support. Advice was freely extended and graciously accepted. Another group was composed of male patients with BDAE severity ratings from 3 to 5. These men were reluctant to participate in group discussion of experiences, and much of the responsibility was placed on the speech pathologists. After encountering this same situation on 2 occasions we concluded that this format was probably not comfortable for them. We recognized the need for a more natural conversational atmosphere, such as card playing, as a possible facilitator to group discussions, with a secondary gain of encouraging these men to socialize in a similar fashion in their own communities.

A third alumni group was composed of men and women who were severely limited with BDAE scores of from 0 to 2. This group caused us much unrest. We felt that the alumni who composed this group were too impaired to benefit from a group process and they were essentially passing the time to allow their families to participate in the support group. The

types of activities which we tried with this group included language stimulation activities, party games such as charades, and dispersing them into other alumni groups. None of these plans proved satisfactory. An integral part of the reunion process has been the post-reunion evaluation by the speech pathologists. Initially, this evaluation focused on the performance of the individual patients. At that time, the speech pathologists were able to share their observations of the communication changes that occurred since the alumni's discharge or attendance at a prior reunion. The discussion shifted to the quality of the adjustment made by the alumni and their families to their homes and communities once hospital support programs were withdrawn. The focus of this discussion turned from the alumni and families toward the important contributions the speech pathologists had made in the rehabilitation process. The significance of this feedback renewed our dedication and enthusiasm. It enabled our staff to see the overall effectiveness of the care provided and has strengthened the efforts the department has been making.

The format of alumni reunions is unique and effective in allowing the speech pathologist to observe former patients and their families communicating in a variety of verbal and situational contexts without re-establishing the "patient role." As a result of the positive experiences gained from the reunions, our Speech Pathology Department suggests that other facilities may wish to investigate the feasibility of initiating a similar program.

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DISCUSSION

Q. Does your facility have a similar program for the patients enrolled in an active treatment program?

A. The concept of "Alumni Reunion" is necessarily reserved for after discharge. However, during active treatment we offer the patient and his family individual counseling. In addition, for the families, a stroke education program that focuses on etiology of stroke and the rehabilitation process is presented by representatives of the multidisciplinary team.

Q. How do you make formal follow-up assessment?

A. Although we recognize the important contribution formal follow-up can make to the knowledge of aphasia and the long term effects of treatment, our facility, operating under the present health care delivery system, is not in a position to formally follow-up patients. It has been our experience that there is a small number of patients who elect to participate in follow-up assessment. This low return rate has occurred after letter and/or telephone reminders that stress the need for individual re-assessments. In our facility, we attribute this reluctance to financial limitations, transportation difficulties and time constraints. Therefore, the alumni reunion has been successful as an alternative means in obtaining information about individual's progress post discharge.

- Q. Have you found that by telling the patient that he may be returning to the reunion as an alumni has been beneficial in terms of terminating the patient from treatment?
- A. Yes, it makes it easier for the patient, his family, and the staff to say their farewells because they all know it will only be a few months until they meet again at the alumni reunion. This takes the finality out of saying goodbye.
- Q. Is there a high relationship between reunion attendance and success achieved during treatment?
- A. It is difficult to answer that question, because success is measured in many ways, including improvement in patients' raw scores, improvement in functional communication skills, improvement in self-image, and improvement in family acceptance and adjustment. There seem to be many reasons why patients and families come to our reunions. Some family members indicated that they wish to return for the advice and support they gain from our staff and from other family members. Some alumni reported that they look forward to reunions as a time to show off their improved skills and learn of the changes made by other alumni. It is the opinion of our psychiatric nurse consultant that many patients and their families return because of the special bond that has been created between them and the speech pathologist.
- Q. Do severely involved patients come to reunions?
- A. The majority of the severely physically handicapped patients discharged from our program do not return to the reunion. We feel that this is due to problems arranging transportation and/or problems arranging escorts. The alumni that have severe communication deficits are represented in our reunion population.