The Midwestern Pennsylvania Stroke Club: Conclusions Following the First Year's Operation of a Family Centered Program

Dr. Glen P. McCormick, Chief
Audiology and Speech Pathology Service
Veterans Administration Hospital

and

Peggy Williams, R.N.
Program Director
Midwestern Pennsylvania Chapter
American Heart Association

Butler, Pennsylvania

Throughout the latter half of calendar year 1974, nurses from the Visiting Nurses Association, Midwestern Pennsylvania, appealed to representatives of the American Heart Association for the creation of services to stroke families in Midwestern Pennsylvania: Armstrong, Butler, Lawrence and Mercer Counties. The nurses, having frequent contacts with stroke-affected families, were alarmed at witnessing the anxieties and problems peculiar to the stroke syndrome.

During the fall of 1974, the Midwestern Pennsylvania Chapter, American Heart Association, joined forces with the Veterans Administration Hospital, Butler, Pennsylvania, and formed: The Midwestern Pennsylvania Stroke Club. Formal meetings began in January, 1975, finding veteran as well as non-veteran family groups participating in monthly, evening meetings. One year later over sixty families of stroke victims had registered with the Club, approximately one-half of whom were from private-sector referral sources.

As stroke families reported for Club pre-registration activities it was abundantly clear that the following conclusions would guide the Club's co-directors:

1. Strokes most often befall families, rather than discrete individuals;
2. Club services would pertain primarily to family-related dynamics, as opposed to patient-oriented services; and
3. Healthful family interrelationships enhance care for chronic disabilities, whereas poor family interrelationships invariably diminish the effectiveness of clinical care, medical as well as behavioral.

At the time of this report, over 90% of all stroke victims served have been male, accompanied to the meetings by their spouse. However, in addition to the husbands and wives, there have been children, in-laws, brothers and sisters, and friends of long standing. Female stroke patients, available within the communities served by the Club, have been slow to pursue participation.

The meetings have consistently been of a socio-educational nature, with a heavy emphasis on education. Early planning of Club programs proved correct in that the stroke families were disinterested in socialization, preferring instead to participate in learning situations providing practical information helpful to family dynamics. Since the majority of families present at the earliest Club meetings had not previously enjoyed opportunities for expressing their fears, lack of understanding or hostilities, the initial Club meetings began with total-group participation followed by separate conferences, one for the stroke victims and a different discussion group for the families and/or friends. Early separation enhanced the discussion of topics which would otherwise prove difficult in mixed company.

Each monthly meeting began with a discussion provided by speakers available from the Club's geographic region. All speakers volunteered their services since the Club was begun (and has operated) on only enough funding for coffee and cookies. The list of topics presented from January, 1975, through May, 1976, follows:

Meeting #	Topic Discussed
1	The causes of stroke; medical/surgical/ rehabilitative care available.
2	Physical management of stroke victims in the home; PT-OT-CT opportunities.
3	Medical question and answer period; the likelihood of recurring strokes.
4	Psychological factors in the face of chronic disabilities.
5	The use and abuse of ego-defense mechanisms: patients vs. families.
6	Outdoor picnic; nomination of forthcoming officers
7	Handling the hostile, un-loving spouse; the emotional aspects of aging.
8	Discussion of architectural barriers; business meeting; election of officers.
9	Death and dying: comparison of family responses to terminally ill patients vs. stroke patients.
10	Cerebral physiology; paralysis and paresis; seizures and anti-seizure medications.
11	Dietary management for low sodium, low cholesterol and diabetic diets; healthful party foods for the Holiday Season.

12 Business meeting; Christmas party; songfest by High School Glee Club.

13 Deep muscle relaxation.

14 Transcendental Meditation.

15 Drugs vs. non-drug therapies for anxietous patients and families.

16 Sexual impotence in brain injured populations.

17 Emotional responses to aging and to changed self-images.

The above-cited topics were selected as the needs of Club members evolved and were expressed. In general, the discussion sequence proved useful to the group. By the sixth meeting, it was no longer deemed necessary during the open discussion period for the stroke victims to be separated from the families and friends.

After seventeen months of meetings, the following conclusions have been reached:

1. The level of suffering experienced by stroke families is far greater than is generally visible from surface behaviors;

2. Stroke patients and their families appear to profit significantly from opportunities for expressing their fears, hostilities and needs.

3. Many of the seemingly overwhelming problems confronting stroke families are resolvable, especially when an impartial observer provides options for the modification of behaviors;

4. The entire range of rehabilitative care extended to stroke families is handicapped in effectiveness by family-borne difficulties subverted by unresolved family distress; and

5. Socio-educational club activities appear to re-vitalize entire family groups, thus enabling ensuing health-related endeavors to have a more immediate rehabilitative effect.

In addition to the more obvious results realized by the clinicians serving the Club, special attention might be paid to the suffering endured by stroke families as a result of inadequate information regarding the illness and associated difficulties. Specifically, it would appear as though clinicians in general are guilty of a form of "academic chauvinism" which erroneously presumes that stroke families are incapable of understanding clinical pursuits and supporting same. Experiences with stroke families tend to point to poor teaching by clinicians rather than to poor learning by families. When properly instructed, stroke families support clinical procedures in a more than adequate fashion.

For clinicians considering the initiation of a family-centered stroke club, the following points are worthy of consideration:

Organization - Many clinicians delay Stroke Club organization until they obtain approval for such from the related medical community. Since formal approval seems problematic, in a number of instances, it appears salient to cite the family counseling nature of the undertaking, which makes frank medical approval a desirable feature rather than a requirement tantamount to failure.

Speakers - Virtually every community enjoys the presence of health specialists capable of supporting the needs of the Club. However, the selection of speakers is of extreme importance since the nature of the group demands that a skilled speaker be able to relate technical information to a lay audience. Practicality thus becomes the order of the day, and, when the needs of the group are not met, the members cease to participate.

Services - The effectiveness of the Club can be evidenced by the families who undertake changes in their daily routine and attitudes. The directors therefore must be prepared to follow through on problem solving, not just identify and categorize complaints.

Sexual Impotence - Sexual difficulties appear characteristic of stroke families. Unfortunately, most stroke families receive little evidence on sexual issues. Since sexual dysfunctioning is very likely to become a topic considered for discussion by maturing clubs, the directors must be prepared to deal forthrightly and effectively with primary and secondary impotence. Unless the directors of the Club handle this topic personally, it is recommended that the speaker(s) be selected from a clinical rather than educational background. Speech pathologists *per se* may be more logical for sexual counseling than is generally thought.

Summary

Strokes typically have an influence on entire families. In the event of unresolved difficulties, family interactions undoubtedly have a negative effect upon the recovery process, leading to lack of efficient responses on the part of the patient, and to a reduction of the physical and emotional wellbeing of the primary caregiver--the spouse.

The wives of stroke victims consistently reported that their greater difficulties came from the unexpected emotional behaviors of their spouses upon their return home. Successful stroke club activities serve to desensitize the families to behaviors typical of stroke patients and educate patient and family for the tasks at hand.

Group cohesiveness appears to develop in stroke clubs in six to nine months. As "old" families become secure in their knowledge of stroke and in their role in club endeavors, they relate rehabilitatively to "new" families joining the group.

The selection of speakers is of significant importance. Issues pertaining to sexual disturbances arise frequently enough to demand specific attention. The rewards of stroke clubs more than offset liabilities. Mature stroke clubs enhance clearer referrals of patients from health sources. Club members serve their communities well as they interact in preventive health programs. The sensitivities of clinicians are greatly expanded by learning of strokes as disturbances to entire family groups.

Questions and Answers

Q. How is your Stroke Club funded?

A. The Club was begun without a budget. It operates on donations and each family has been asked to contribute twenty-five cents per meeting to cover the cost of coffee. The wives rotate in making cookies. The speakers all serve gratis. Mailing expenses have been minimal. Basically it's a function based upon volunteered services.

Q. What has been the response of physicians to the Club?

A. We wasted an inordinate amount of time trying to get a firm response from our local medical society. For a variety of reasons this process dragged on until we simply announced in writing that we were beginning the Club. Since the Club is primarily a family-centered activity--with family members free to do as they wish--we felt secure in beginning our programs without direct medical support. At this point in time our physicians have come to appreciate our services and would resist efforts to have them stopped.

Q. How much trouble have you had finding speakers?

A. Finding speakers per se has not been a problem. Finding speakers who understood stroke families and language disturbed persons has been quite difficult. Apparently, speaking effectively to a lay audience is more difficult for people like us than we care to admit.

Let me also stress that the choice of a speaker on the topic of sexual impotence is especially difficult. Mrs. Williams and I recommend a clinical rather than sex-education oriented person. In addition, especially since the role of nurses and speech pathologists serving as sex counselors is as controversial as it is, I personally feel that nurses and speech pathologists--after proper training--may, because of built-in sensitivities, have a role to play in this area which, up to now, we have ignored. General researchers have referred to sexual intercourse as a form of human communication and, as such, I personally feel that speech pathologists might look into this as a new area of responsibility.

Q. How did you choose your sequence of topics?

A. By listening to the families of stroke patients Mrs. Williams and I came to sense the general lack of knowledge they had. We moved forward one meeting at a time, developing as we went a lecture sequence to cover both the physical and emotional aspects of stroke. Since there is so much that stroke families don't really understand about their difficulties, virtually anything one talks about has impact. I firmly believe that we, in failing to prepare families for future events, cause a great deal of the confusion and suffering via our oversight and/or poor teaching.

Along these lines, let me say too that the wives of stroke patients have indicated unanimously that their greatest problems derived from the unpredicted and unexpected changes in the stroke patient's emotional patterns following his/her return home. Consequently, we are building a video tape library of stroke-related information to be viewed by stroke families during the time the patient is in active rehabilitation programs. In this fashion we hope to educate the families during the time that they previously have wasted in anxious, unproductive moments. After each educational tape has been viewed, a face-to-face meeting between the spouse and Service representative will be arranged. Hopefully this will better prepare the families for forthcoming responsibilities and stresses. If the tapes work as well as we hope, perhaps we can share them with other facilities.

Q. Why has your Club not dealt specifically with language therapy?

A. Our Club has not intended to deliver services directly to patients. Instead, we have tried to reduce family friction and thus establish a better environment for communication to take place. We feel as though we have been successful in this. The wives in particular have learned to better understand their predicament and, even when changes in behavior were not forthcoming, the spouse has been more correct in the assignment of guilt or frustration. We have learned very clearly that the spouse of a stroke patient is a very definite clinical ally <u>if</u> he/she is educated sufficiently. In failing to educate the spouse, we as clinicians predispose the effectiveness of our therapy to failure or to intrigues which significantly prolong our task.