

Critical Factors Associated with the Success or
Failure of Community Stroke Clubs

Sara B. Sanders
Veterans Administration Medical Center, Memphis, Tennessee

Ellen I. Hamby
University of Tennessee, Knoxville, Tennessee

Mariann Nelson
Memphis, Tennessee

As a result of the authors' involvement with community stroke clubs and with the American Heart Association, it became apparent that existing booklets, pamphlets, and brochures pertaining to stroke clubs presented information to the reader in such a way as to imply that there was only one way to organize and carry out the operation of a stroke club. As available information was somewhat dogmatic in stating what should be done in order to have a successful club, the American Heart Association elected to compile a manual on the formation of stroke clubs, demonstrating that there were no hard and fast rules for organizing and operating a club, and that the key word should be "flexibility."

Preliminary to preparing this manual, a questionnaire (Appendix) was developed and distributed to 302 clubs or sponsors in 48 states. The questionnaire was divided into seven categories, with questions designed to elicit information regarding (1) club meetings, (2) club structure, (3) club membership, (4) financial support for the club, (5) programs and activities of the club, (6) history and organization of the club, and (7) problems and suggestions. Respondents also were asked to report on factors which they believed to contribute to the success or the failure of their stroke club and to offer advice to those persons who were in the process of organizing a new club.

A total of 118 questionnaires were returned by spokespeople of 109 clubs still in existence and nine clubs which were no longer active. These responses were from stroke clubs in 29 states and represented over 2500 stroke persons or their family members. The responses to the questionnaires were tabulated, and the data were compiled and published in a manual to assist a sponsoring agency or a core group of individuals in organizing a stroke club or rejuvenating an existing stroke club.

Since reference to a speech pathologist appeared on 78%, or 92, of the questionnaires, it appears that there are many clinicians working directly or indirectly to assist stroke people in their reentry into the community. In some instances, the professionals played only a minor role, but, in other instances, the professionals were quite active. Whether the speech pathologist actually participates in a stroke club, trains students to treat the "whole person," or refers the stroke family to community resources at the termination of therapy, clinicians all share in the stroke individual's success or failure in community reentry. Thus, from the standpoint of the professional, it is necessary to know when to lend assistance and when to "keep hands off" a support group. The purpose of this presentation is to share some of the results of our project with you. Although a number of categories were incorporated into the questionnaire, the focus of attention

during this presentation will be on the problems encountered in the formation of stroke clubs, problems affecting the maintenance of the club, and suggestions for dealing with or avoiding these problems. The final focus will be on those factors which existing clubs consider to be responsible for their success or failure, and on advice from existing clubs to new clubs.

Problems in Formation and Maintenance of a Stroke Club

The responses to the survey suggested that the problems tended to fall into three general categories; problems among members, problems relating to the structure and organization of the club, and problems with attendance and membership.

Problems Among Members. There was some degree of overlap between problems among members in forming and in maintaining a stroke club. Many of these problems might be anticipated merely by recognizing human characteristics. In forming a stroke club, the problems centered around lack of interest, lack of commitment, lack of leadership, and inability to integrate different impairments. Once the club was formed, initial interest occasionally waned, personal jealousies and resentments developed, or cliques occurred. The more handicapped members sometimes began to feel uncomfortable as their disabilities became more evident compared with those of less handicapped club members. As a result, communication barriers (such as aphasia and dysarthria) became more difficult to overcome, and new members had difficulty feeling comfortable. Also, because it became more difficult to maintain leadership among stroke people, professionals too quickly took over the running of the club.

Many of the problems which related to personalities or attitudes might be avoided or solved by enhancing member participation. Specific suggestions offered by stroke club representatives to enhance member participation included the following: get members more involved in committees, telephoning, visitation, and projects; let stroke people themselves run the stroke club; change officers frequently so that leadership roles could rotate. Problems could also be avoided if the membership understood the roles of the officers, the steering committee, the advisor, and the sponsoring agency. It was also important for members to feel wanted. Establishing host couples to greet the members and to identify and welcome visitors helped to alleviate feelings of awkwardness at the meetings. Other suggestions offered for avoiding problems among members were: set up a buddy system to foster care, concern, and communication; point out members' contributions or achievements; and deal forthrightly with all subjects, i.e., finances, death, and sex.

Problems in Structure and Organization. The problems associated with the structure or organization of a stroke club which were identified as impeding the formation of the club could be avoided by good preliminary planning. The most frequently cited problems were poor organization, lack of financial support, difficulty obtaining a sponsor, difficulty setting up good programs, and difficulty determining the membership of the club. With regard to membership, some clubs reported difficulty in deciding if only stroke persons could be members or if persons with trauma, brain tumors, congenital brain damage, etc., could be included in the membership. Also, once the membership criteria were established, often there was difficulty in determining the types of available memberships. Most clubs offered full memberships for stroke people and associate memberships for family members, friends, or professionals.

Once the club was established, the problems in structure and organization pertained mainly to programs, leadership, and club recognition. The two problems which arose with programs were generating a list of new program ideas and coordinating programs for people with old and new strokes. Stroke people in the acute phase of their recovery frequently had different needs than those who had had their strokes several years previously. It was often difficult to interest both groups in the same program. With regard to leadership, it was often difficult to continue selecting good officers from year to year or from term to term. As a result of being unable to get new officers who were interested in and capable of serving, the same leaders were selected and offices were rotated. In the long run, this might produce "burn-out" which could be an impossible problem to overcome. Two additional problems which were cited by the respondents were community apathy and the lack of goals or projects to increase the cohesiveness of the group.

The suggestions for avoiding or solving these problems both in forming and in maintaining the stroke club were: (1) Have a training session for the stroke club steering committee, officers, coordinators, and sponsoring agency. (2) Have a strong business base. (3) Insure adequate funding. (4) Obtain good programs. (5) Keep up-to-date on current matters relating to stroke. (6) Have enough volunteers. (7) Obtain good community support. (8) Have stroke people as the leadership. This last suggestion was reported to be the most important.

Problems in Attendance and Membership. The final group of problems was associated with overall attendance and membership. These problems were fairly similar regardless of whether they occurred during the early formation of the stroke club or whether they occurred within existing clubs. The primary problem seemed to be lack of transportation, which directly affected attendance at meetings. Not only was it impossible for some stroke people to ever get to a meeting, but it also was difficult for some members to continue coming when they had to depend upon someone other than a spouse to provide transportation. A second problem centered around a lack of referrals or a lack of continued referrals. Whether we like it or not, we are somewhat dependent upon the physician to point the stroke person in our direction. Referrals will be received from the sponsoring agency, from the community, and from the various rehabilitative services, but a number of stroke people see no one other than a physician. Not only must the newly formed club depend upon a core group of members who will attend regularly, but the existing club also must depend upon new members to sustain attendance as well as to provide new leadership. Closely related to the problem of lack of referrals was the lack of sufficient publicity. Initial publicity seemed to be easier to obtain than continuing publicity for an already existing club.

Suggestions for avoiding or solving the problems associated with membership and attendance included: Increase the quantity and quality of publicity. Break into small groups if the membership is too large. Provide transportation and adequate parking. Improving physician input or relationships with physicians. Two suggestions were offered by the respondents relative to the initial attendance or continued inclusion of new members. These suggestions were: (1) Have a stroke club member visit the hospitalized stroke person and immediately place his/her name on the mailing list. (2) Have a new stroke person visit the stroke club before his or her discharge from the hospital.

Factors Contributing to the Success or Failure of a Stroke Club

The recipients of the questionnaires were asked to think back to the initial formation of their community stroke club and to mentally review their course of activity. If their club was a success, they were asked to specify the factors they considered to be responsible for that success. If it was deteriorating or was now defunct, they were asked to share the factors they felt to be responsible for the failure. Many of the factors which were cited as being responsible for the failure of a number of community stroke clubs were the same problems identified in the formation of the club. If these problems could be avoided by preplanning, failure of the stroke club might be avoided. These factors were: lack of overall interest, lack of participation by stroke persons, poor health of the members, bickering among members, lack of a strong volunteer base, lack of time by coordinators/professionals, problems with agreement on meeting time, lack of new members, lack of transportation, lengthy business meetings, and lack of follow-up of potential members. Two of these factors warrant explanation. The factor pertaining to coordinators/professionals related to those few clubs who had a paid coordinator or an agency representative or professional who did the major portion of work. The factor relating to meeting time applied more to areas where a second club existed, and the club which admitted to failure was actually consumed by another club which met at a more convenient time.

A number of factors were identified as being critical to the success of existing stroke clubs. As might be anticipated, several of these factors pertained to relationships or attitudes among members. These factors were: (1) the enthusiasm or interest of the members, (2) the positive attitude of the members toward the club, (3) friendships among members, (4) maintenance of strong core groups, (5) the concentration on successes rather than failures by the group as a whole and by individual members, (6) recognition of members' accomplishments, (7) the sharing of experiences after stroke, (8) the establishment of an atmosphere in which members felt needed, (9) having a key, inspirational person in a leadership position, and (10) having the spouses' support of the club.

Other factors which were critical to the club's success were those which pertained to the organization or structure of the club. These factors included (1) strong sponsoring agencies, (2) a strong steering committee, (3) a strong slate of officers, (4) good programs (educational rather than social), (5) no fund raising, (6) community recognition, (7) professional continuity, (8) good preplanning, (9) social activities in addition to educational programs, and (10) independence from supervision.

With regard to attendance and membership, the only two critical success factors were persistence in recruitment by the members and/or sponsoring agency or steering committee and a monthly newsletter which most clubs used to publicize their meetings and activities. Interestingly enough, although many respondents mentioned the lack of transportation and the lack of physician referrals as the two primary problems in forming and maintaining a club and considered these as critical factors in the failure of some clubs, no one considered the solutions to these problems as the reasons for their success. It may be that these are unsolvable problems.

Advice to New Stroke Clubs

As a final review of information included on the questionnaire, the respondents offered a variety of advice to those persons who were in the

process of organizing a new stroke club. These suggestions were an attempt to pass on to others the benefit of their own experiences. Some of the more frequent suggestions are cited below. It should be remembered that these were suggestions rather than rules which must be adhered to strictly.

1. Attempt to get as much support as possible.
2. Don't get discouraged.
3. Send a newsletter to members at least monthly.
4. Have programs which are relevant to stroke people.
5. Encourage stroke people in self-improvement.
6. Have a list of prospective members.
7. Form a professional advisory council.
8. Be an educational group.
9. Be sure there's a need for a club in the community.
10. Gear meetings to the needs and desires of the membership.
11. Be realistic about the type of service you hope to render.
12. Avoid getting too formal in structure.
13. Have a direct referral source.
14. Involve stroke people in the ground floor of organization.
15. Open the doors to everyone who is interested in joining.

Conclusion

This project was one of the first major efforts to canvass the stroke population and to include them in the evaluation of support groups organized for their benefit in the community. By having access to this information, clinicians directly or indirectly involved in community reentry for the stroke person can better determine the needs of existing stroke groups or can assist an interested core of individuals in organizing such a group. If more thought and planning occur in the early stages of the organization of stroke clubs, and if some means of evaluation can be found to determine the effectiveness of the group, perhaps the stroke family rather than the professional can assume more of the responsibility for the maintenance of the stroke club.

REFERENCES

Sanders, S.B., Hamby, E.I., and Nelson, M., You are Not Alone. Nashville: American Heart Association, Tennessee Affiliate, 1984.

DISCUSSION

- Q: This may be an unfair question because I don't believe you have the data. Therefore, I will ask it in a hypothetical sense. Do you think that some of the problems the stroke clubs have talked about in terms of interactions among the groups could be reflective of different distributions of right hemisphere damage versus left hemisphere aphasic patients? Could this have contributed to some of the problems relative to the mix within the groups?
- A: I think so, to a certain degree. I don't have data from a wide range of patients, but I do think there is a difference. We have found that problems can arise between the left hemisphere aphasic patient with minimal speech and the right hemisphere patient who is more verbal. On the other hand, I didn't mean to mislead you, that it is only the stroke

patients who have problems. We also have turf problems among spouses and among professionals. So, yes, I do think some difficulties arise because of the types of stroke people involved, but I don't think that is the only problem we see among members.

Q: You have a long list of problems and I realize that was a good share of what you were after, but did you get a feel from the questionnaires that people felt it was worth the effort to maintain a stroke club despite the problems?

A: Yes, and I think the fact that 109 of these clubs are still trying to stay together is an indication of that. They are not all complete successes, but only nine clubs who returned the questionnaires have actually gone by the wayside. In fact, in Florida they have 24 clubs and these are very active clubs. On the other hand, I think that the questionnaires were very positive, although they enumerated a lot of problems. We have to remember that this is not one club sending in all of these problems, but it is a compilation of many clubs with many different perspectives. I think one thing that emerged throughout the responses was that stroke people need to run their own clubs. If they did, there were fewer problems listed. If the clubs were run by others, such as a visiting nurse association or professionals at a specific facility, then more problems tended to be seen from the perspective of the stroke person.

Q: Why do you think there are so many clubs that are successful? What are they providing to the patients?

A: A number of things. One of the most important things, I think, is that they're answering a need for socialization. I think that they recognize that here are other people that they can identify with who have similar problems, although perhaps not to the same degree that they have. So many of the things that we try to do is to get the stroke people into the community. I think a theme that ran throughout the questionnaires was that the stroke club was a place that the stroke person can go to share the hurts and the feelings and the disabilities that they have. I do think that there is common ground here. I think it is just as important for the stroke club to be a support for the spouse also. In many cases, the stroke person attends stroke club meetings because the spouse chooses to do so.

Q: Do you have any data from your group or are you aware of any data that indicate that aphasic patients who participate in the stroke club maintain the gains obtained in treatment after treatment is over more than people who do not participate?

A: I have no data, but I have been involved in the stroke club in Memphis for six years. I firmly believe that those who participate in our stroke club are involved in community activities and that they are probably the most independent people that I know. The ones I see that come back to our clinic that have been at home with no stimulation appear to be the ones whose skills diminish with time. I'm not saying that perhaps a stimulating household could not do the same thing for them as a stroke club, but I am saying that for many patients, the stroke club may be their only stimulation. I do think that the stroke club keeps the patient functioning at his maximum if they take an active part. It would certainly be a good study to do if we could control the environment enough to determine if it was indeed the stroke club that was making the difference.

Appendix

STROKE CLUB QUESTIONNAIRE

American Heart Association
Tennessee Affiliate
Stroke Rehabilitation Subcommittee

MEETINGS

1. At which of the following locations are your regular meetings held?

<input type="checkbox"/> Private home	<input type="checkbox"/> Senior citizens center
<input type="checkbox"/> Hospital	<input type="checkbox"/> Community center
<input type="checkbox"/> Nursing home	<input type="checkbox"/> Church
<input type="checkbox"/> Speech and hearing center	<input type="checkbox"/> Other -- Specify:

2. Please indicate the factors you believe to be important in the selection of a meeting place.

<input type="checkbox"/> Location	<input type="checkbox"/> Attractiveness
<input type="checkbox"/> Parking	<input type="checkbox"/> Type of facility. What types of facilities would you/would you not select?
<input type="checkbox"/> Accessibility	<input type="checkbox"/> Other - Specify:
<input type="checkbox"/> Cost	

3. When and how often are your meetings scheduled?

<input type="checkbox"/> Midweek	<input type="checkbox"/> Morning	<input type="checkbox"/> Weekly
<input type="checkbox"/> Weekend	<input type="checkbox"/> Afternoon	<input type="checkbox"/> Biweekly
	<input type="checkbox"/> Evening	<input type="checkbox"/> Monthly
		<input type="checkbox"/> Bimonthly
		<input type="checkbox"/> Quarterly
		<input type="checkbox"/> Other - Specify:

4. Please indicate the format of a typical meeting by numbering the following items according to the order in which they occur in your meetings. (1=first event; 11=last event)

<input type="checkbox"/> Prayer	<input type="checkbox"/> Old business
<input type="checkbox"/> Introduction of members	<input type="checkbox"/> New business
<input type="checkbox"/> Program	<input type="checkbox"/> Correspondence
<input type="checkbox"/> Minutes of previous meeting	<input type="checkbox"/> Social period/refreshments
<input type="checkbox"/> Treasurer's report	<input type="checkbox"/> Other - Specify:
<input type="checkbox"/> Committee reports	

5. What is the average length of your meetings?

<input type="checkbox"/> ½ - 1 hour	<input type="checkbox"/> 2 - 2½ hours
<input type="checkbox"/> 1 - 1½ hours	<input type="checkbox"/> 2½ - 3 hours
<input type="checkbox"/> 1½ - 2 hours	<input type="checkbox"/> Other - Specify:

CLUB STRUCTURE

1. Which of the following officers does your club have? Briefly describe the major function of those officers.

_____ President. Function.

_____ Vice-President. Function:

_____ Secretary. Function:

_____ Treasurer. Function:

_____ Program Chairman. Function:

_____ Other - Specify:
Function:

2. Which of the following individuals may serve as officers?

_____ Stroke victims
_____ Spouses

_____ Professionals
_____ Other - Specify:

3. What is the procedure utilized in the election of club officers?

_____ Nominated and elected by committee
_____ Nominated by committee; elected by club members
_____ Nominated by club members; elected by committee
_____ Nominated and elected by club members
_____ Other - Specify:

4. What is the length of the term to which the officers are elected?

_____ 4 months
_____ 6 months
_____ 1 year

_____ 2 years
_____ Other - Specify:

5. What agencies serve as sponsors of your club?

_____ Heart Association
_____ Medical Center
_____ Civic club.

_____ University
_____ Sorority/fraternity
_____ Other - Specify:

6. What is the major function of the sponsoring agencies?

- Advising
- Organizing and planning meetings
- Conducting meetings
- Other - Specify:

7. What committees does your club have?

- Membership
- Publicity
- Newsletter
- Contacts (telephone, letters, etc.)
- Fund Raising
- Other - Specify:

8. How is the membership of these committees determined?

- Members are assigned to committees.
- Members are elected to committees.
- Members volunteer to serve on committees.
- Other - Specify:

MEMBERSHIP

1. What is the approximate membership of your club?

- 20-40
- 40-60
- 60-80
- 80-100
- Other - Specify:

2. What is the average attendance at your regular meetings:

- 20-40
- 40-60
- 60-80
- 80-100
- Other - Specify:

3. How do you encourage regular attendance at meetings?

- Newsletter
- Phone contacts
- Radio/TV announcements
- Other - Specify:

4. How do you secure the names of potential members?

- Physicians
- Physical, occupational and/or speech therapists
- Nurses
- Social workers
- Other - Specify:

5. How are new club members typically recruited?

- Newsletter
- Phone contact
- Personal visit
- Radio/TV announcements
- Other - Specify:

FINANCIAL SUPPORT

1. From what sources does your club receive financial support?

- | | |
|------------------------------------|--|
| <input type="checkbox"/> Dues | <input type="checkbox"/> Fund raising events |
| <input type="checkbox"/> Donations | <input type="checkbox"/> Other - Specify: |

2. If your members pay dues, what is the amount of those dues?

3. If your club has sponsored fund raising events, please indicate the types of events that have been sponsored.

4. For what purposes are your monies utilized?

PROGRAMS/ACTIVITIES

1. What types of programs/activities has your club had?

- | | |
|--|---|
| <input type="checkbox"/> Speakers | <input type="checkbox"/> Panel discussions |
| <input type="checkbox"/> Films | <input type="checkbox"/> Member involvement |
| <input type="checkbox"/> Musical entertainment | <input type="checkbox"/> Other - Specify: |

2. What types of programs/activities have been most successful?

- | | |
|--|---|
| <input type="checkbox"/> Speakers | <input type="checkbox"/> Panel discussions |
| <input type="checkbox"/> Films | <input type="checkbox"/> Member involvement |
| <input type="checkbox"/> Musical entertainment | <input type="checkbox"/> Other - Specify: |

3. Who is responsible for arranging your programs?

- | | |
|-----------------------------------|---|
| <input type="checkbox"/> Officers | <input type="checkbox"/> Sponsors |
| <input type="checkbox"/> Members | <input type="checkbox"/> Other - Specify: |

4. If your club is involved in activities other than those scheduled for your regular meetings, what kinds of activities do you have?

PUBLICITY

1. What types of publicity does your club utilize?

Radio/TV
 Letters
 Pamphlets
 Medical staff

Newspapers
 Word-of-mouth
 Therapists
 Other - Specify:

HISTORY/ORGANIZATION

1. What is the name of your club?

2. How long has your club been in effect?

3. Please list personnel/organizations which you think are important resources in planning, forming, or maintaining a stroke club.

4. Do stroke victims take an active role in the club's plans?

5. What problems did you encounter when forming your group?

6. What problems have been encountered in maintaining your group over time?

7. In your opinion, how might these problems be avoided?

8. To what do you owe your success or failure as a stroke club?

9. What advice would you give to a club just organizing?

PLEASE RETURN THIS QUESTIONNAIRE NO LATER THAN JANUARY 10, 1982.