Self-Help Groups and Client Perception

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Introduction

The purpose of this report is to discuss the roles of self-help groups before and after treating stuttering and to describe the ways in which stutterers perceive clinicians and speech therapy. The viewpoint is that of a client, and a great deal of the information is from verbal sources encountered by the author; this material will not be found in referable texts. As such it is open to argument, but discussions with many clinicians, stutterers and self-help groups have revealed patterns of attitude which, while difficult to quantify, are nevertheless real.

In view of the diversity of attitudes among stutterers, it is unwise to generalize, so an attempt will be made to convey a picture of this diversity that makes the treatment of stuttering and maintenance of improvement so difficult.

The author is a scientist (a biologist) and has been involved with stuttering, stutterers, clinicians, therapy, and self-help groups for 57 years. He also stutters and has been exposed to a wide variety of therapies.

Client Perception — the Late 19th and Early 20th Centuries

Before 1930 most people with severe stutters were burdened by despair and fear. Their rejection by society made them anxious about any social contact, and the types of treatment available did not live up to the promises of the practitioners. Speech therapy was a lucrative field for charlatans (and still is in some countries) and many stutterers developed a scepticism about therapy and therapists that was well founded.

The majority of therapists were perfectly genuine, but they did not have a scientific basis upon which to work or techniques that succeeded outside the clinic. There was reliance on relaxation and distraction, with only ephemeral benefits. Maintenance, which is still a problem today, was an almost insurmountable obstacle earlier this century. It was difficult to practise learned techniques outside a clinic at a time when there were no self-help groups and when stutterers tended to shun the company of other stutterers who could have participated in maintenance exercises.

Many stutterers in the late 19th and early 20th centuries encountered brutality inside and outside the clinic; at school and in the workplace they were ridiculed and penalized by their peers, and in clinics the browbeating of clients and even ill-advised surgery were commonplace. It is not surprising that many stutterers were bitter about speech clinicians, withdrew from society or tended to misanthropy.

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Client Perception — the 1930s to 1980s

Even in the 60s there was a hangover from those days, and many stutterers in Europe, including myself, looked upon most therapies and therapists with extreme scepticism. In North America, however, the stuttering-modification therapies developed between 1930 and 1960 period in the Iowa and Michigan schools began to humanize speech therapy and encourage stutterers to have a better image of themselves, less fear of social contact and more confidence in clinicians and the methods they used.

In my own case it was not until 1972, when I was exposed to Iowa/Michigan-type therapy with a dash of psychotherapy at the Royal Ottawa Hospital, that I developed confidence in the clinicians and the treatment; many clients of my vintage had the same experience. We felt that at last the therapists knew what was going on behind our stuttering facades, and were delighted when we were asked to share our feelings and problems and participate in the design of the therapy. The approach appealed to our intelligence, which distraction had never done.

Although gains were considerable and many stutterers became almost completely fluent within the clinic, carrying the improvement over into the everyday world needed a degree of vigilance and discipline that was nearly impossible to keep up every hour of every day, and there were disappointments. Some clients reverted to their old speech patterns, and some were bitterly sceptical.

During the 70s fluency-shaping techniques using operant conditioning to treat stuttering began to dominate the treatment scene. The Webster program and its offshoots focussed on the mechanics of speech, attempting to replace bad speech patterns with good ones, without paying much attention to the inner fears and conditioned responses of stutterers to difficult speaking situations. These techniques dominate stuttering therapy in the United States today and are widely used in Canada. Many clients are pleased with the results of fluency-shaping therapy, but some feel that the treatment of a stutterer as a person is given too little attention. Some clients were so conditioned to stutter in certain situations and to respond to even indirect stuttering cues that they had difficulty using the better ways of speaking; these people said to other stutterers, not necessarily to the clinicians, that they resented the therapist's overlooking the pressing personal, inner problems associated with their speech behaviour.

In the past 4 years there has been in Canada a tendency to humanize the impersonal, arms-length operant conditioning approach of fluency shaping by including treatment for attitude and even psychotherapy. In some clinics, for example at the University of Alberta, the approach is comprehensive and eclectic. Techniques of easy onset and block modification, adapted from Van Riper, are combined with other fluency skills into a structured program designed to shape fluency, expand social skills and develop a positive attitude. It is all set within a framework of operant conditioning that is well hidden; there is great emphasis on maintenance. This type of program, which is flexible and can be tailored for individual client's needs, is making it possible for even those clients many therapists dismissed as untreatable to establish much better levels of fluency.

Speech science is progressing very rapidly and methods of treatment are changing; there is a feeling of hope in the air, both by therapists and by clients, that has not been evident before. At the same time, self-help groups for stutterers are proliferating at a bewildering rate, and many of these groups provide facilities for maintenance exercises, and so become an extramural component of the clinical picture.

In spite of the numerous rays of hope that are lighting the stuttering scene, there are still old-fashioned and even bad therapies applied by therapists reluctant to learn and use the new methods. Consequently there is a large number of disillusioned and even bitter stutterers who no longer apply for treatment, but struggle to cope with life handicapped by the ball-and-chain of a severe stutter. The people who come to clinics for help are the tip of the iceberg; there are many more who refuse to be treated or to get involved with self-help groups or even to acknowledge that they have severe problems. It is here that self-help groups can help bridge gaps in the pretreatment-treatment-maintenance continuum.

The Client-Clinician Relationship

The client-clinician relationship is complex. When the stuttering-modification approach is used, there is close contact between the clinician and the client over long periods, so close that at times emotional bonds are forged that interfere with the therapy. The fluency-shaping approach is more at arms-length, with electronic monitors to some extent replacing the close contact of the client with the clinician. Although this has the advantage that the client does not become dependent on the clinician, some clients resent the impersonal approach.

Whatever method is used, there is an unspoken contract between the client and the clinician; the clinician agrees to use his or her skills to reduce uncontrolled dysfluency and the client agrees to persevere and follow instructions to the best of his or her ability. Without this contract, both client and clinician are wasting their time.

If treatment fails to help, the client may well feel let down and disappointed, while the clinician, no matter how professional, may have a feeling of guilt that the approach could have been better. Stuttering therapy can be an emotional business, and it is surprising how in most clinics there are few signs of client friction, and it is heartwarming to see how clients support each other; sometimes the clients support frustrated clinicians. This is far different from the situation earlier this century, when therapy frequently involved confrontation and threats. I know many stutterers of my age who developed a strong dislike of their belligerent therapists in childhood; this seldom occurs today.

The Functions of Self-Help Groups

Self-help groups have many roles to play both before and after therapy, and the antipathy that some clinicians have to these groups is hard to understand because these extramural groups are a necessary part of the therapy-maintenance continuum. It can only be concluded that some clinicians are not aware of the different types of self-help groups and their many functions.

In brief, self-help groups fall into two categories: the *social groups* and the *maintenance groups*, with many groups performing both social and maintenance functions.

Social Groups

The *social group* in its pure form has nothing to do with therapy. Its function is to form a supportive community of stutterers in either a town, a province or a state, or a country; some social groups have chapters in many cities. Good examples are the National Stuttering Project and Speak Easy International Inc., both in the United States, Speak Easy Inc. in Canada, the P-clubs in Scandinavia, and the Pebble Club (Der Kieselstein) of Germany. The membership of these clubs consists mainly of stutterers, but there are some parents and friends as well as clinicians.

These social groups, most of which exist on very little money, provide a forum for stutterers in their newsletters, encouragement for the despairing and lonely closet stutterers, advice about how to get assessment and treatment, a lobby for human rights, and points of contact for lonely people living in the glass tower of a stutter. Some provide a hot-line stutterers can call when social pressures become so great that they contemplate suicide, which occurs more often than most people realize.

Most groups do not encourage stutterers to use the organizations as wailing walls, but nevertheless they allow stutterers to express their frustrations and state their problems in a positive way. These groups permit severe stutterers to discover that they are not alone and can survive even with a stutter; for many it is the first time they have encountered real friends who understand their predicament and will take the time to listen to their hesitant speech. For some it is the first time they have

held a conversation or a discussion. The groups also help stutterers to manage their fear of stuttering, creating situations whereby stutterers can speak before sympathetic audiences of carefully selected size and stress content without fear of ridicule or censure; this function has been of immense help to stutterers who have not had speech therapy or have not responded to it, as well as to those who have had partial success with therapy. Success breeds success, and felt fluency breeds better fluency and increases confidence.

Groups with sufficient financing sometimes help severe stutterers who cannot afford the costs of therapy, but these are few and far between. The social groups impinge on therapy to the extent that they encourage stutterers to apply for treatment, which needs motivation, determination and more than a little courage. They also help to deal with many stutterers' low self-esteem.

Maintenance Groups

The *maintenance group* in its pure form emphasizes practising the speaking techniques learned in a particular clinic. There are groups for fluency shaping and groups for stuttering modification that are loosely attached to the clinics where these methods are taught. Examples are the groups associated with the Clark Instititute in Toronto and with the University of Alberta in Edmonton. A clinic seldom supplies funds but may provide accommodation for meetings, monitoring instruments (on loan) and speakers; sometimes a clinician will attend as a guest to ensure that correct speaking techniques are being used. Nevertheless, the group is run by and for stutterers, most of whom have had therapy, and the main objective is maintaining the speech improvement.

The group meetings frequently begin with a warm-up session with each person standing up and using exaggerated techniques (e.g. prolongation, easy onset, cancellation, air-flow and phrasing) before moving to more difficult assignments. The members criticize each other's speech in a positive way. These groups may also have social functions, but these are usually secondary to the objective of maintenance.

These maintenance groups are invaluable in the post-therapy period and help the clients to maintain the disciplines needed to practise and use the learned techniques.

Development of Social Skills

Both social and maintenance self-help groups help stutterers to develop social skills. This is particularly important after therapy, where a newly fluent stutterer can become a boring babbling brook and hold the floor to such an extent that other speakers cannot say their piece. Debate and calm discussion can be learned to replace the stutterers' aggressive or diffident attempts to participate in verbal give and take; the stutterers learn to assemble the facts and concentrate on what they have to say rather than wrestle with anxieties about the repetition and blocks that impeded previous attempts to speak. It takes time to learn these skills, and not all of them are taught in clinics.

Self-help groups can play many useful roles in speech rehabilitation, which involves management of speech techniques, of anxiety and of social skills. The clinics cannot deal with all of these over-extended periods; self-help groups can, at low cost.

Problems of Self-Help Groups

Many self-help groups for people who stutter have difficulty increasing and maintaining membership and surviving financially. There is a widespread reluctance by stutterers, particularly those who have not received therapy, to join any stutterers' organization because they feel ashamed of their disability and membership labels them as stutterers. People who stutter are often unrealistic about their handicap to the extent that they deny its severity to themselves and to their peers; they try not to notice the stuttering themselves and hope that others will do the same. For some, the 'stutterer' label is hard to accept. Then there are the stutterers who avoid the company of other stutterers because they see a reflection of their own handicap in the speech of others; they prefer to go it alone. Many stutterers are so fearful of social involvement that they cannot bring themselves to participate in any group activity at home or in the workplace; they withdraw. The social self-help groups in particular have difficulty increasing or even maintaining their memberships for these and other attitudinal reasons.

Clinicians seldom see the multitude of closet stutterers or those who deceive themselves that they do not need help; speech-language pathologists only deal with those who have come into the open, recognized their disability and decided to do something about it, as well as those referred to them by schools, employers or courts, sometimes in spite of client reluctance. The social self-help groups help the stutterers of this hidden world and try to persuade them to come into the open, but it is uphill work without financial support.

The maintenance self-help groups are more secure, but even so regular attendance at meetings is usually a small fraction of the total membership. Most stutterers who have had treatment and improved their speech want to maintain their gains and are willing to make some effort to do so; at least for a short time after treatment most attend meetings regularly. But the original impetus tends to fade unless it is restored by clinical refresher courses. Clients who respond well to therapy and maintenance tend to stop participating in the groups when they feel that they no longer need them for support, forgetting that the role of all members of self-help groups is to help others as well as themselves; the more they control their stuttering, the more they can help less fluent members. Nevertheless, these maintenance groups have great potential value as a follow-up to therapy, provided they are given the support by members and funding agencies.

Human nature clouds most clinical and social pictures, and self-help groups are no exception. Some of the social groups accuse the maintenance groups of elitism and isolationism, and some maintenance groups will not participate in social groups where many members have not had therapy or have had different therapy. Although some maintenance groups participate actively with social groups, all too often this is not the case; the schism is unfortunate because both types of group have a great deal to offer.

The scepticism and even hostility of a few clinicians to self-help groups in general and to social groups in particular has not helped membership. When asked why they feel hostile, clinicians often say either that the groups tend to promote the idea that stutterers can get along without therapy or that they provide the stutterers with information or attitudes with which the clinicians do not agree. Some feel that the maintenance groups trespass on their clinical territory; an honest few will confess that they feel threatened by maintenance groups because they could reduce the need for jobs in speech-language pathology. A minority simply feel that self-help groups are unprofessional. These negative attitudes do not help the stutterers, whether they have had treatment or not.

Future Roles of Self-Help Groups

One of the main problems in treating stuttering is maintenance. The difficulty is not only one of techniques and client self-discipline, but also one of logistics. There is a flow of clients through the clinic where they receive therapy and there are refresher courses, but in the post-clinic phase there is a build-up of clients needing assistance over long periods. Stuttering is not something that can be cured, but the techniques that can be learned to control it must be practised for the rest of the client's life unless he or she rapidly becomes fluent and remains fluent with little effort, but these are the fortunate minority.

It is not realistic to expect that clinics can handle this build-up of treated clients needing help with maintenance; the pressures on accommodation and clinicians, and the money needed for travel and possibly for clinic fees are too great. Few clients can afford the cost of repeatedly travelling long distances from their homes to the clinic and pay for accommodation near the clinic, and there are not enough trained clinicians to go around. It is here that self-help groups can play a vital role by assisting with maintenance (including attitude improvement, management of fear of stuttering and management of social skills), thereby getting better returns on the investment of time, effort and money in therapy. Self-help groups can increase maintenance efficiency and reduce costs and pressures.

With more financial support, a more systematic network of self-help groups than the present one could be established throughout Canada, where, because of the distances involved, clients who have had therapy urgently need local maintenance facilities. The present network of maintenance groups could be a starting point, but at present these groups tend to be isolated and unaware of the existence of other groups; it is most difficult to locate most of them, and no catalogue of them exists. Better still, the maintenance groups could be integrated more closely with the social groups, because both have valuable roles to play in the post-treatment phase. But this will not happen without central planning and additional money.

Many self-help groups, particularly the social groups, resent any attempt by officials or clinicians to control their activities; they cherish their independence. If any effort is made to incorporate them into a semi-official national network it will be necessary to persuade them that the social aspects of their activities can be independent; the maintenance activities, however, will need some degree of integration with the clinics and clinicians. There could even be a few itinerant clinicians whose main job would be to systematically visit the self-help groups, advise on maintenance procedures and even consult with individual clients with special problems after treatment. The advantage would be that in each town or city there could be self-help loci where clinicians could come and advise or consult, instead of the patients having to go to the clinic a long distance away and take time off work.

In order to achieve this, the network of just the maintenance groups could be increased, financed and organized, but ideally the social groups should be a part of the system, even if only loosely. The ideal type of self-help group is envisaged as one that brings the social and maintenance aspects under the one umbrella. Within each of these groups there could be subgroups solely concerned with maintenance. If some members have been treated at a clinic using fluency shaping while others have been through another clinic using stuttering modification, and others have been through an eclectic program using many different techniques, then maintenance subgroups could be formed to practise individual techniques. In addition to these maintenance activities clients could play a social role within the main self-help group to help themselves and others.

Financing

The costs of medical treatment are increasing at a time when governments are trying to cut back on medical funding. When government health-care systems pay for treatment, it is in the interests of the government to provide funding to support self-help activities and thereby reduce expenditures on formal maintenance activities within the clinics. This would free clinicians to treat more stutterers, because they would not need to spend so much time on the post-treatment phase. Most major clinics treating stuttering have more applications for treatment than they can handle, and less maintenance work would enable clinicians to reduce the backlog of clients

waiting for therapy. Provided a self-help group networking plan is available, a project to establish such a system that would make treatment more cost effective could be a candidate for government funding.

Conclusions

The perception of clinicians by clients has greatly improved in the past 50 years. Before 1930 many stutterers who had been unsuccessfully and often unwisely treated were sceptical and even hostile towards therapists struggling to provide the best available treatment on a very flimsy scientific basis. When the stuttering modification techniques of the Iowa and Michigan schools were developed, they systematized and humanized speech therapy and client-clinician relations greatly improved, but there were still disappointments in the maintenance of gains of fluency outside the clinic. Later use of operant conditioning techniques in therapy improved the effectiveness of treatment, but maintenance problems persisted and are still a major obstacle today.

It is considered that self-help groups could play a role in the maintenance phase. They could help to achieve better results for less cost if a systematic network of self-help groups involved in both maintenance and social activities were to be established with close linkages to major clinics providing therapy. Some of the maintenance problems arising from logistics and client costs could be reduced by using self-help groups as an extension of treatment, regarding them as an essential part of the treatment-maintenance continuum. As the approach would make speech therapy more cost effective, the system could be a candidate for government funding.

Before the system can be established a great deal of research on self-help group organization will be necessary, together with careful planning of network establishment and management, and finding out how best to integrate clinics and clinicians with the maintenance activities of the groups without interfering with their independence and autonomy.

Summary

The failure of speech therapists earlier this century to help people who stutter resulted in many stutterers having a low opinion of clinics and clinicians. In the past 50 years, however, with the introduction of stuttering-modification and fluency-shaping techniques, therapy has been much more effective, and clients now have more confidence in the clinicians and the methods they use. Nevertheless, failures in maintenance still cause major disappointments, and self-help groups could greatly assist in the difficult post-treatment phase if they were organized and expanded.

The different types of self-help group for people who stutter (the social groups, the maintenance groups and those with both functions) are described. It is suggested that if a more formal self-help group network were established and integrated with clinics and clinicians, it could play a vital role in increasing the effectiveness and reducing the costs of the difficult maintenance phase following treatment for stuttering. Because such a network would reduce the costs of treatment, it might well be a candidate for government funding. A great deal of planning and research will be necessary before such a network can be established and become a part of the pretreatment-treatment-maintenance continuum without interfering unduly with the autonomy of the client-run groups.