
Therapeutic Experiences of People Who Stutter

Expériences thérapeutiques relatives au traitement du bégaiement

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Abstract

This qualitative study investigated the experiences of seven adults who stutter. The study focused on what the participants had to say about those experiences which had either been detrimental or beneficial to them in their efforts to modify their stuttering. An initial 60- to 90-minute, semi-structured interview, using open-ended questions and probes, elicited the participants' narratives of their experiences of stuttering. A second 60-minute interview assessed the credibility of the investigators' preliminary interpretations. Understanding and relationship were the primary themes that emerged from the analysis of the transcripts. Participants saw the essence of their success in ameliorating their stuttering as being the increase in their knowledge of the nature of stuttering, and most especially, their deepened understanding of their own experience of stuttering, and their resulting ability to both modify and cope with it more effectively. This process of change took place in the context of nurturing relationships.

Abrégé

Cette étude qualitative examine les expériences de bégaiement et de traitement de sept bégues adultes. Une première entrevue semi-structurée de 60 à 90 minutes, comprenant des questions ouvertes et des demandes de précision, a permis aux participants de faire le compte rendu de leurs expériences. Une seconde interview de 60 minutes visait à évaluer la crédibilité des entrevues préliminaires de l'enquêteur. Les relations humaines et la compréhension sont les thèmes principaux qui se dégagent de l'analyse des transcriptions. Selon les participants, le succès du traitement tient essentiellement à une meilleure connaissance de la nature du bégaiement et, plus précisément, à une compréhension plus approfondie de leur expérience personnelle qui leur ont permis de modifier le bégaiement de d'y faire face plus efficacement. Cette évolution a eu lieu dans le contexte d'une relation enrichissante. Les résultats mettent l'accent sur le rôle important des relations humaines au cours de l'intervention thérapeutique.

This article reports on the findings of a qualitative study which investigated the experiences of adults who stutter. In line with qualitative methodology, the principal investigator listened to the stories participants told about their experi-

ences of stuttering, in order to discover the meaning they gave to these experiences (Brody, 1991).

This study marks a departure from past trends in stuttering research where questions concerning the experiences of people who stutter were not investigated because the subject matter did not readily lend itself to quantification. This point has previously been made by Quesal (1989) when he contended that scientists investigating stuttering "rather than accepting these psychosocial aspects as being real, but very difficult to quantify, they seem to have decided that difficulty in quantification means a lack of reality" (p. 162). As a result, the reality of what it is to be a person who stutters has not been systematically investigated.

Qualitative research methodology can provide a deeper understanding of the experiences of people who stutter. In May of 1992, a special issue of *Topics in Language Disorders* appeared under the co-editorship of Westby and Erickson. Westby and Erickson asserted that "those interested in language are moving beyond the sole use of quantitative methodologies to new approaches, i.e., the use of more qualitative procedures" (p. iv).

Patton and Westby (1992), writing in the same issue of *Topics in Language Disorders*, provided a succinct description of what qualitative research entails: "Qualitative researchers talk with people about their experiences and perceptions." (p.3). They went on to describe some of the strengths and limitations of qualitative and quantitative research methods. The former study "real-world situations as they unfold naturally" whereas the latter investigate "behaviour in experimentally controlled situations" (p.5). Furthermore, a quantitative approach:

...makes it possible to measure the reactions of a large number of people to a limited set of questions and to use a statistical analysis in comparing group data. In contrast, qualitative methods typically produce a wealth of detailed information about a much smaller number of people and cases. This increases understanding of the cases and situations studied, but reduces generalizability (p.4).

The key for the researcher is to select the approach that is appropriate to the purpose of the investigation.

Qualitative methods have already been used within the practice of medicine, because of the increasing importance given to understanding the patient's experience of illness, rather than limiting care to the treatment of disease. Weston, Brown, and Stewart (1989) described some of the critical differences between disease and the illness experience of sickness:

Disease is an abstraction: the "thing" that is wrong with the body-as-machine; illness, on the other hand, is the patient's personal experience of sickness: the thoughts, feelings, and altered behaviour of someone who feels sick.... The biomedical model is a conceptual framework for understanding the biological dimensions of sickness by reducing sickness to disease. The focus is on the body, not the person. A particular disease is what everyone with that disease has in common, but the illness experiences of each person are unique (p.147).

In a similar vein Kleinman (1988), in *The Illness Narratives*, stressed the importance of soliciting the patient's and family's stories of illness so that the personal reactions may be obtained, and treatment not be limited to the disease. Brody in *Stories of Sickness* (1987) highlighted the importance of obtaining the patient's story: "Suffering is produced, and alleviated, primarily by the meaning that one attaches to one's experience. The primary human mechanism for attaching meaning to particular experiences is to tell stories about them" (p. 5).

In addition to these clinical applications of the qualitative approach, two further examples are presented from other fields of research. Epidemiology, seeking to determine the health of populations, has found it helpful to supplement quantitative surveys with life stories and other quantitative data (Evans, Barer, & Marmor, 1994), particularly when studying disease risk factors (Jones, 1986).

The field of health service research provides another example in a study investigating possible means of providing appropriate support for caregivers of Alzheimer patients. In this instance, the qualitative studies were found to be more helpful than the quantitative ones. For example, a randomized controlled trial found that an intervention, focusing on education and respite support, did not reduce caregivers' emotional stress (Mohide, Pringle, Streiner, Gilbert, Muir, & Tew, 1990). In contrast, qualitative research revealed that the context of the past relationship of the caregiver with the patient was an important element in the present experience of the caregiver (Morgan, 1992). This finding resulted in different interventions being suggested than those offered by randomized controlled trial of Mohide et al.

The application of the qualitative paradigm with people who stutter would enrich and strengthen therapy by allowing treatment to become more deeply rooted in the person's lived experience of stuttering, as recounted in their stories. The stuturer's lived experiences would be analogous to the illness experiences described by Weston et al. (1989) and Kleinman (1988).

These stories of people who stutter would contain the meaning that stuttering has had during the various phases of their lives, as well as the impact of stuttering on a diversity of personal relationships and life choices. By listening to the narratives of people who stutter, speech-language pathologists could gain a far richer understanding of the client's experience of stuttering than could be obtained by structured interviews and standardized questionnaires. Most importantly, the therapist could acquire deeper comprehension of the meaning that stuttering has for the client, and, as emphasized by Brody (1987), it is this deeply personal meaning that mediates the amount of suffering a person experiences because of stuttering.

This investigation of the experiences of people who stutter is in line with the work of Wendell Johnson (1946), who stressed the importance of understanding the contribution that attitudes and cognitions make to the diagnosis and treatment of people who stutter. Building on Johnson's work, Corcoran (1991) reiterated the need to investigate the ways in which stuttering affects a person's life, and the meaning that persons who stutter give to their experiences.

The present study used qualitative methods to study the experiences of people who stutter. This approach permits the investigation of topics which are of intense clinical importance, but are poorly suited to quantitative methodology.

Method

This study obtained narratives from seven adults who stutter. It focused on what the participants had to say about those experiences which had either been detrimental or beneficial to them in their efforts to modify their stuttering. The co-investigators examined the thoughts, emotions, motives, and meanings described by the participants during semi-structured interviews.

Sample

In line with qualitative methodology, the investigators purposefully selected a sample of seven participants to express their experiences of stuttering and therapy. Maximum variation sampling was used to obtain a diversity in age, gender, and types of therapy. This strategy was employed in order to obtain central themes that emerged from participants with diverse make-ups (Crabtree & Miller, 1991; McCracken, 1988; Patton, 1990).

Five men and two women who stuttered participated in this investigation. The participants ranged in age from 25 to 50. Three of the participants were high school graduates. One was currently enrolled in university, while two were university graduates, and one held a graduate degree. Their occupations ran the gamut from farmer, health professional, to engineer.

All seven of the participants either had been, or presently were, enrolled in stuttering therapy. Four had received a form of fluency shaping therapy, while two received a form of stuttering modification therapy, and one participated in both forms of therapy. Based on the clinical judgement of the interviewer, the stuttering severities of participants at the time of the interview were rated as follows: two were severe, two were moderate, and three were mild.

The severity of stuttering during interviews was not related to type of therapy. Of the two participants who received a severe rating, one had completed fluency shaping therapy and the other stuttering modification therapy. In the case of the two participants who had received a moderate rating, one had completed a fluency shaping program, while the other was still enrolled in that type of therapy. Of the three participants who had received a mild rating, one had completed fluency shaping therapy, the second had completed stuttering modification therapy, and the third had completed both a stuttering modification and a fluency shaping form of treatment.

Interview

With one exception, each person participated in two 60- to 90-minute interviews. A month intervened between each interview. One person participated in three interviews, because the length and complexity of this participant's responses necessitated an additional session so that all the questions could be responded to. This addition of an extra session is in line with qualitative methodology which stresses flexibility of research design (Patton & Westby, 1992). The interviews were semi-structured, using open-ended questions and probes designed to elicit the participants' stories of their experience of stuttering (see Appendix). While only one of these questions dealt directly with the participants' experience of speech therapy, i.e., "What role has speech therapy played in your experience of stuttering?", the participants often spoke of experiences other than therapy which had either a positive or negative effect on their stuttering, e.g., "How has stuttering affected your relationship with your family?"

The purpose of the first interview was to obtain the participant's description of his or her experience of stuttering. The second interview served to assess the credibility of

the investigator's preliminary interpretations of what had been described in the first interview by asking the participant to comment as to the accuracy of these interpretations. In addition, during the second interview the investigator asked the participant to clarify and amplify themes that had emerged during the first interview. All interviews were carried out by one investigator (JAC).

Credibility

As noted by Patton and Westby (1992), the personal and individual nature of qualitative research precludes the attainment of objectivity. The principle analogous to validity in quantitative research is the credibility of the qualitative findings. In the present study several methods were used to enhance credibility.

First, all interviews were initially tape-recorded and then transcribed verbatim. Second, during all phases of the research, the investigators, following the advice of McCracken (1988) and Patton (1990), attempted to bracket out previous professional biases regarding stuttering in order to better understand the participants' experience of stuttering. For example, prior to the interview stage, the investigators explored with each other their personal biases regarding stuttering and its treatment. These biases were then taken into account at all phases of the project, in order to better understand the participant's perspective without the interference of the investigators' preconceptions. Third, during the second interview, the investigator employed the process of member checking by which he told each participant of the themes that had been derived from the first interview. He then asked each participant to comment on the appropriateness of these themes in capturing the experiences recounted in the first interview (Kuzel & Like, 1991). Fourth, triangulation involved the process of obtaining multiple perspectives on a phenomenon in order to arrive at a more complete understanding (Kuzel & Like, 1991). In the present study both co-investigators read the transcripts from all of the sessions in order to obtain a deeper and more comprehensive understanding of the themes (Lincoln & Guba, 1985). The investigators' joint analysis led to a mutually derived classification of the relevant quotations. While considerable discussion took place, no significant disagreements occurred between two investigators.

Analysis

The data for this study were the transcribed responses given by participants during their interviews. These were analyzed by both investigators in order to identify major themes. The investigators employed the inductive procedures of immersion and crystallization. The investigators immersed themselves in the reading of the transcripts. The themes that

emerged were crystallized and enriched through the discussion of the investigators (Denzin, 1989; Crabtree & Miller, 1991).

Findings

Understanding and relationship were the primary themes that emerged from the analysis of the manuscripts. The participants spoke about the degree to which their relationships with parents, teachers, mentors, and therapists were either detrimental or beneficial to them in their efforts to understand and modify their stuttering. Detrimental relationships were marked by a lack of understanding on the part of both the participant and either a parent, teacher, or therapist. In contrast, beneficial relationships were characterized by a process whereby the participants' initial state of confusion about their stuttering was transformed by a relationship with a fellow stutterer or therapist. It was within the context of such a beneficial relationship that the fellow stutterer or therapist, to varying degrees, shared their understanding of stuttering with the participant. The following sections contain quotations that illustrate this interplay between understanding and relationship.

Detrimental Relationships

Barriers to receiving therapy. None of the participants spoke of being involved in stuttering therapy as children. Most often they reported that their parents did not seem to know what to do to assist them. Speech-language pathologists generally were not available to them in the schools they attended. (Three of the participants attended primary school during the 1950s, two in the '60s, and three in the '70s.) Consequently, the parents and children were left to their own devices, resulting in needless suffering. Quotes from three of these participants describe such experiences.

Parents' lack of understanding resulted from the absence of reliable information about the nature and treatment of stuttering. In this case, not knowing what to say to their son, they remained silent:

I think my parents have probably been at their wits' end as to what to do about it. Back in the early '70s, there really were very few viable resources to which one could turn in regards to speech and they didn't know what to do. And we never really discussed it.

Lack of acknowledgement and support was evident. Participants described how their need for help was not perceived by parents. Indeed, one participant was ignored and left to face her experience of stuttering without maternal support:

As I became older, it was a relative in the family who said to my mother: "Did you ever consider giving her speech therapy?" And she [her mother] said: "Well, I never really thought of it...." I found out later that he [her brother] was receiving speech therapy for his stuttering at the high school because we were not at the same high school....And it irked me no end that, why was he getting it and that I wasn't?"

Another participant described the painful consequences that the absence of an understanding relationship with her parents had on her life:

I didn't talk to them [her parents] about stuttering at all....That would have been the top thing in my mind, if only I could talk to them about my stuttering....I'm trying to think why it was so difficult. I think because we just didn't have the kind of relationship where we talked about anything important.... It was very factual information, not feelings. I didn't know how to get started. I didn't know how to break that wall until the end of high school. I was just at the end of my rope. I just couldn't help but cry about it, and I had to stay home from school because I was so upset.

Teacher's effort to help. All the participants spoke of the pain they experienced because of their stuttering while in school. This quote illustrates how a teacher's lack of understanding led to an inappropriate remedy to the painful situation in which the participant found himself:

[In] about grade five I had to give a speech...in English class. And I chose the topic of "dogs." And I got up and said, "Today I want to talk about - ." I couldn't say the word "dog" for love nor money and I sat in tears. The teacher came over and patted my back, and said "no problem, everything's fine." But he moved me from where I was sitting to the side board along the wall. So when he asked me questions in class, I could get up and write the answers down on the chalk board. Which looking back on it now...probably's not the way to deal properly with somebody like that.

Unsuccessful therapy. Therapy that was not built on an understanding relationship was criticized by the participants. One participant spoke of an unsuccessful therapy experience which he saw as depending on "tricks" rather than on the understanding of stuttering:

I did take some therapy when I was in grade 8. I went to a therapist, I quote, "who believed it was all tricks." She sort of taught me, well if you're having trouble, you get into a rhythm, you tap your foot, you pinch your leg. Anything to get started.... She

did nothing mentally at all. Now, I don't think that helped me much at all.

A second example of an unsuccessful therapy experience resulted from the failure of the therapist to establish a relationship with the participant, thereby misunderstanding him:

I did go to a hospital once and got some speech therapy, but it just wasn't successful for me. It didn't work because I think the person I had it with, really, I think she really didn't want to sort of be teaching me. Or didn't want to deal with me, sort of. She listened to me but didn't really want to get involved. We had interviews and that's all it was.... What she concluded wrongfully is that she thought I didn't have a problem because I could talk [fluently] with her.

Beneficial Relationships

Beneficial relationships were characterized by a therapist or fellow stutterer sharing their knowledge of stuttering with the participants. This sharing gave rise to feelings of hope, a sense of being supported, and an awareness of not being alone.

Fellow stutterers. Interactions with others who stuttered allowed the participants to begin to break down the barriers of isolation. A participant described how the example of two men who had overcome their stuttering gave the participant hope that, someday, the same would be true for her:

[Two mentors who had overcome stuttering] gave me hope that maybe someday I could overcome my stuttering. They are the only positive influences, the only beacons of hope, because everywhere else, what I was reading and seeing was: you have to accept it, you're always going to have the problem, face up to it sort of thing, and I was rebelling against that all along because of these two people. If they can do it, I can do it, you know.

The support and understanding of another person who stuttered provided the added dimension of feeling truly understood by a fellow sufferer:

I think having a friend [who stutters], who we can call up, and give each other support when we're feeling down or just to practise. I think that has been so good, and it's an understanding and we know that when we're with each other we'll speak more clearly.

An extension of this special understanding and support is at work in stuttering self-help groups:

I think that's the reason self-help groups are so good, [is] because for the first time the person feels: "I'm not different from these people. We all feel the same and it's okay. I can talk however I want. It's okay here."

Speech therapists. When the participants described the positive effects of speech therapy, they spoke of a new understanding of their stuttering, a decrease in their fears, their newly acquired speaking skills, and changes in the way they lived. First, their quotes speak of the benefits of understanding. In the next quote, the participant speaks of the benefits of having his own experience of stuttering understood by others:

When I went into therapy, the results were so quick, so immediate for me. Because I felt all of a sudden that there were people who understood me and I didn't feel so alone. And I think that quickly had an effect on how I felt. And I had also just come out [by openly declaring that he was a homosexual], so there were a lot of things being dealt with, all at the same time. And I think that quickly had an effect on how I felt.

The second quote speaks of the participant's deepened awareness of the dynamics of his own stuttering, and the ways he could modify it:

But I think that probably, more than anything [else about speech therapy], what helped was the fact that I understood then what was happening and understood there were ways to modify it.... Knowing that I could do something about it probably changed it right then and there, more instantaneously than anything, was that I knew I could overcome it with some effort and with some help.

The following quote points to the importance of clients clearly understanding the reason(s) for their using a specific therapeutic technique. Without this knowledge or insight, which takes time to acquire, a client can misuse a technique learned in speech therapy and thereby undermine their progress:

The most recent thing that happened to me, and this is only about a month old now, [is how] I'd been using all my [speech] targets...to improve my speech, to sort of increase my chances at lucky fluency is how I treated it.... And it was not until about a month ago, that I said, "I shouldn't be doing this [using his speech targets to avoid stuttering]. Like this is not the purpose of all this stuff. It's to work through a word, even while I'm having a block, it is to be able to call in a target, lie it down and somehow work through this thing." And it was not until then that I realized, hey, that's what it's

about. You know, it's sort of like a light came on, you know. And I was very, very pleased, and it took almost three years since therapy to realize this.

The understanding gained by the participants resulted in a diminution of their fears:

I guess that's what any kind of therapy is all about. Sort of brain therapy is about. By talking about things and understanding them, the fears go away.

Why I think it [speech therapy] was effective? Well I went from being somebody who is afraid most of the time to someone who wasn't. I mean, I was able to concentrate on my life as opposed to worrying about speaking all the time.... It was understanding what was going on. I also learned ways of sort of speaking easily, which I sometimes use. So it (speech therapy) just made life easier. I didn't have to put so much energy into the plotting, the planning and the anticipating.

It's quite funny how, [I] mean, how when you can use the phone without even thinking about stuttering. How different it is from fearing the phone ringing. I mean it's a totally different experience.

The last two quotes tell of how progress in speech therapy brought about a change in the way the participants viewed the more personal parts of their lives. In the first case, the result was a change in an important external relationship. In the second case, a change came about in the way the participant viewed herself, resulting in a decision to seek psychotherapy:

And I think speech therapy was the downfall of the [love] relationship [with my partner]. Because I was very, I was very docile and very sort of pliable at that point. And then I became more assertive [in the relationship].

As time went on [while I was in speech therapy], a lot of psychological problems arose that I had to face.... So it meant that I was going to see a psychiatrist and that was painful because I really didn't think I needed one. But as a result [of speech therapy, I discovered that] I did need one.

Discussion

The participants' growing understandings about the nature and experience of stuttering took place in the context of relationships. Indeed, it had been just such a lack of understanding which had earlier disrupted their relationships with their parents. The findings of this study highlight the importance to the person who stutters of being understood

by the other, whether it be a parent, teacher, fellow stutterer, or therapist. Without such understanding, the stutterer will be left alone with his or her experience of stuttering, which will only intensify the suffering.

Implications for Therapy

These findings are in agreement with the point of view espoused by Brody in *Stories of Sickness* (1987) and Kleinman in *The Illness Narratives* (1988), when they argued that obtaining the patient's story of his or her illness experience is a critical element in effective health care. Therefore, obtaining the stutterer's narrative of his or her experience of stuttering should be an essential part of the diagnosis and treatment of people who stutter. This process of story telling will have at least two benefits. First, the telling of this story will enrich the understanding of both the client and therapist. Secondly, the recounting of such a deeply personal and painful experience will likely deepen the relationship between them.

When the participants described their positive therapeutic experiences, they spoke of the importance of understanding and relationship. Participants saw the key to their improvement as being the increase in their knowledge of the nature of stuttering, and most especially, their deepened understanding of their own experience of stuttering, and their resulting ability to both modify and cope with it more effectively. This process of change took place in the context of nurturing relationships.

While the findings indicate that the participants' relationship with their therapist or fellow stutterer was one of the factors critical to their progress, the role of relationship in stuttering therapy is often at risk in current therapeutic practice, even to the point where clinicians are reluctant to treat people who stutter. Kalinowski, Armson, Stuart, and Lerman (1993), building on previous research, found that clinicians' perceptions of stutterers were significantly more negative than clinicians' perceptions of themselves. Speech-language clinicians perceived stutterers as being "guarded, nervous, tense, reticent, insecure, and hesitant" (p.84). The authors suggested that one of the factors sustaining this negative stereotype was "the speech-clinician's difficulty in maintaining long-term amelioration of the disorder following symptomatic therapy" (p. 85).

Such symptomatic therapy concentrates on what Weston et al. (1989) and Kleinman (1988) described as the disease aspects of a disorder. In the case of stuttering, focus is concentrated on the symptoms of stuttering, with the result that the experience of the person is often ignored. In large part, it places at the heart of therapy the disorder of stuttering and the ways in which it can be modified and reduced. Such a limited clinical focus ignores the benefits that may arise

when a person's experience of stuttering assumes a significant role in therapy. There then arises the possibility spoken of by Weston et al. that the inclusion of the person's experience:

may be helpful by alleviating fears, correcting misconceptions, encouraging him to discuss his discouragements, or simply by "being there" and caring what happens to him. At the very least this compassionate concern is testimony to the fundamental worth and dignity of the patient [client] (p.151).

A synthesis of the findings of this study reveals that the three elements most important to the improvement of stuttering are: (a) the person's deepened understanding of both the nature of stuttering and their own personal experience of stuttering; (b) their resulting ability to more effectively modify and cope with their stuttering; and (c) supportive relationships. The presence of these conditions allowed the participants to change the way they experienced their lives.

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Appendix

Questions and Probes Used During the Interviews

1. How has stuttering affected the way you live your life?
 - a. as a child in primary school
 - b. while in high school
 - c. while in university or college
 - d. since completing your education

2. How has stuttering affected the important relationships in your life, for example, with your _____?
 - a. family
 - b. friends
 - c. teachers
 - d. members of the opposite sex
 - e. spouse
 - f. children
 - g. employers
 - h. co-workers

3. How would you live differently if you did not stutter.
 - a. What would you do that you don't do now?
 - b. What would you stop doing that you do now?

4. How has stuttering affected your sense of self-esteem, i.e., the way you have valued yourself over the course of your life?

5. What are the ways in which you have felt shamed or stigmatized because you stutter?

6. How has stuttering affected the way you look at the future?

7. What role has speech therapy played in your experience of stuttering?

8. Has stuttering had any positive effects on the way you live your life?