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A Qualitative Study of First-Person Accounts of Living with a Stutter

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To the Graduate Council:

I am submitting herewith a dissertation written by Peter James Columbus entitled "A Qualitative Study of First-Person Accounts of Living with a Stutter." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Psychology.

Howard R. Pollio, Major Professor

We have read this dissertation and recommend its acceptance:

Michael Johnson, Ronald Hopson, Harold Luper

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

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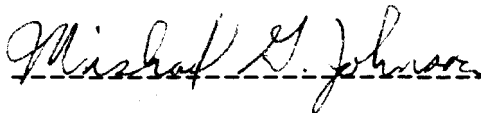
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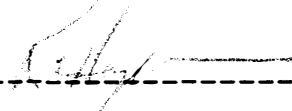
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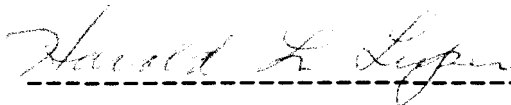


Howard R. Pollio, Major Professor


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and recommend its acceptance:







Accepted for the Council:



Associate Vice Chancellor
and Dean of the Graduate School

A QUALITATIVE STUDY OF FIRST-PERSON ACCOUNTS
OF LIVING WITH A STUTTER

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Peter James Columbus

August, 1992

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ABSTRACT

Eight males and four females who stutter were interviewed regarding their everyday life experiences with stuttering. The interviews were analyzed using a qualitative, intuitive/inductive method. Results revealed four major experiential themes: The Burden of Stuttering, Living with Difference, Living with Constraints, and Negotiating Life. The Burden of Stuttering theme refers to the participant's experience of the effort involved in discoordinated speech, contending with interactional order between self and other, effectively communicating spoken messages, and their uncertainty about the occurrence of stuttering and listener reactions to it. Living with Difference refers to experiences of dissimilarity between self and fluent speaking others; this difference may be experienced in terms of stigma, prejudice, and alienation. Living with Constraints refers to limits imposed by stuttering and reactions of other people to it. Specific constraints are experienced in terms of limits on the quality and quantity of spoken expressions, as well as in terms of educational and job discrimination, and social relationships. Negotiating Life refers to the unique process of coming to terms with one's life as a person who stutters.

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CHAPTER 1

INTRODUCTION

This research is about the experience of living with a stutter. The World Health Organization (1977, p.202) defines stuttering as "disorders in the rhythm of speech, in which the individual knows precisely what he wishes to say, but at the time is unable to say it because of an involuntary, repetitive prolongation or cessation of a sound". Surveys of the prevalence of stuttering in Europe and America show that about 1 percent of the population stutters (Bloodstein, 1987). It is estimated that three times as many males as females stutter (Andrews, 1984), with the median age of onset at 4 years (Andrews, Craig, Feyer, Hoddinott, Howie, & Neilson, 1983). Although the cause or causes of stuttering are unknown, current theoretical perspectives portray stuttering as a genetic (Kidd, 1984), anticipatory struggle (Bloodstein, 1984), operant (Costello, 1984), prosodic (Wingate, 1984), cognitive-linguistic (Hamre, 1984), sequencing and timing (Mackay & MacDonald, 1984), and/or temporal programming (Kent, 1984) disorder.

There is strong evidence to indicate that stuttering is not a neurotic response (Andrews, et al., 1983; Bloch & Gooldstein, 1971; Bloodstein, 1987; Sermas & Cox, 1982). Andrews et al. (1983), for example, reviewed studies

focusing on the personalities and neuroticism of people who stutter. These studies variously used the Sarason General Anxiety Scale for Children (Andrews & Harris, 1964), the Structured Psychiatric Interview (Andrews & Harris, 1964), the Eysenck Personality Inventory (Hegde, 1972), the California Test of Personality (Prins, 1972), the Minnesota Multiphasic Personality Inventory (Horlick & Miller, 1960; Lanyon, Goldsworthy, & Lanyon, 1978; Pizzat, 1951), and the Spielberger Anxiety Scales, (Molt & Guilford, 1979; Zenner & Sheperd, 1980). On the basis of a careful review of the data, Andrews et al. (1983, p.229) conclude that "no differences in personality factors related to neuroticism have been demonstrated in controlled studies of unselected populations".

Despite these findings, there are a number of stereotypes in everyday life about people who stutter. Stereotypes are typically defined as "overgeneralized, largely false beliefs about members of social categories that are frequently, but not always, negative" (Jones, et al., 1984, p.156). Stereotypes of people who stutter, however, are almost always negative and consist primarily of undesirable personality characteristics. Children, adults, males, and females who stutter are described in unfavorable ways by parents, teachers, employers, college students, children, store clerks, speech pathologists, and fluent speakers. The following provides a brief history of

research on stereotypes of people who stutter since 1970. This review will focus mainly on the stereotypes of speech clinicians, teachers, parents, and employers.

Stereotypes of People Who Stutter: Speech Clinicians

A study by Yairi and Williams (1970) found that the ten most frequently mentioned traits by speech therapists concerning elementary-school boys who stutter were (in order of frequency): Nervous (39%), shy (32%), withdrawn (28%), tense (28%), anxious (27%), self-conscious (24%), insecure (24%), sensitive (22%), quiet (20%), and intelligent (19%); only "sensitive" and "intelligent" were rated as desirable. Woods and Williams (1971) obtained a list of adjectives used by speech clinicians in regard to adult males who stutter and compared these with adjectives obtained by Yairi and Williams (1970) for children. Results indicated "a fairly well established stereotype of a [male] stutterer regardless of age" which mainly consisted of negative personality characteristics. In this study, approximately 75% of the clinicians provided adjectives that fit within the category "nervous or fearful" whereas 64% of the clinicians provided adjectives that fit into the category "shy and insecure". Woods and Williams (1971) observe that only 31% of the adjectives had to do with abnormal speech.

A second study by Woods and Williams (1976) found that speech clinicians used adjectives to describe men and boys who stutter that were different from those used to describe men and boys who do not stutter, and that the adjectives used to describe the former groups were similar and largely unfavorable. As in their previous study (Woods and Williams, 1971) they concluded that a strong, negative stereotype exists regardless of the age of the male stutterer.

The attitudes of speech clinicians toward women and girls who stutter were not studied until the early 1980's. In the initial study by Silverman (1982), an attempt was made to clarify whether clinical stereotypes of females who stutter were different from those of males who stutter, and whether such stereotypes were different from stereotypes of girls who stutter. One-hundred-sixty speech-language pathologists completed 47 semantic differential scales with reference to one of the following eight different constructs: A Girl, A Girl Who Stutters, A Boy, A Boy who Stutters, A Woman, A Woman Who Stutters, A Man, and A Man Who Stutters. Across corresponding categories of the age and sex of constructs, clinicians rated the person who stutters more negatively than a person not labeled as a stutterer. In addition, clinicians tended to have more negative impressions of females and children who stutter. The strongest impressions were of "A Girl Who Stutters", who

was rated by clinicians as boring, unsociable, bungling, uninfluential, pessimistic, aimless, insubstantial, sensitive, and excitable.

Ragsdale and Ashby (1982) also used semantic differential scales to study speech-language clinicians' connotations of four different constructs: Boys Who Stutter, Adult Males Who Stutter, Girls Who Stutter, and Adult Females Who Stutter. In contrast to Silverman (1982), Ragsdale and Ashby (1982) found that these constructs -- boys who stutter, girls who stutter, adult males who stutter, and adult females who stutter -- were perceived in similar, negative ways regardless of the age or sex of the item being rated.

In a study concerned with clarifying the stereotypes speech clinicians hold of young female and male children who stutter, Horsley and FitzGibbon (1987) used the Woods and Williams (1976) semantic differential scales and eight hypothetical constructs: a typical preschool girl, a typical 8-year-old girl, a typical preschool girl stutterer, a typical 8-year-old girl stutterer, a typical preschool boy, a typical 8-year-old boy, a typical preschool boy stutterer, and a typical 8-year-old boy stutterer. Like Silverman (1982), Horsley and FitzGibbon (1987) found that an unfavorable stereotype was present for all stuttering constructs, and that age and gender of the construct being rated had differential effects on the strength of the

reported stereotype. In contrast to Silverman (1982), however, the strength of the negative stereotype was greatest for school age boys.

Cross-cultural variables influencing the stereotypes held by speech clinicians were studied by Cooper and Rustin (1985). They administered the Clinician Attitudes Toward Stuttering Inventory (Cooper, 1975) to 371 clinicians in the United States and 331 from Great Britain. Results showed significantly more British clinicians (63%) than American clinicians (32%) believed that most people who stutter have psychological problems while a majority of clinicians from both countries believed that people who stutter possess characteristic personality traits (U.S. 52%; G.B. 54%), have distorted perceptions of their social relationships (U.S. 55%; G.B. 57%), have distorted perceptions of their stuttering behavior (U.S. 71%; G.B. 79%), and have feelings of inferiority (U.S. 67%; G.B. 57%).

Research on the education level and clinical experience of speech clinicians suggest that these factors either have no influence on stereotypes (St. Louis and Lass, 1981; Turnbaugh, Guitar, and Hoffman, 1979), lessen the strength of the stereotypes over the course of clinical training (Horsley and FitzGibbon, 1987), and/or strengthen the negative stereotypes through years of clinical practice (Ragsdale and Ashby, 1982; Yairi and Williams, 1970). The above studies, however, are all cross-sectional and,

therefore, do not reflect the development of individuals or groups over time. In a study designed to determine shifts in the attitudes of speech clinicians over time, Cooper and Cooper (1985) administered the Clinicians' Attitudes Toward Stuttering Inventory to 674 speech clinicians throughout the United States over a ten year period from 1973 to 1983. Results showed that responses to three inventory items regarding people who stutter and their personalities significantly changed in the ten year period. In 1983 fewer clinicians agreed that people who stutter have psychological problems (34%, 1983; 44%, 1973), that people who stutter hold distorted perceptions of their own stuttering behavior (71%, 1983; 91%, 1973), and that people who stutter have distorted perceptions of their social relationships (55%, 1983; 75%, 1973). No changes were found over the ten year period regarding clinicians' perceptions that people who stutter have feelings of inferiority, and that people who stutter possess characteristic personality traits.

Most studies concerning the attitudes of clinicians toward people who stutter have been done "prior to full implementation of Public Law 94-142, licensure bills, upgraded national and state certification requirements and continuing education opportunities for service providers" (Lass, et al., 1989, p.129). Lass et al. (1989) sought to determine if speech clinicians' perceptions of people who stutter have changed since the introduction of legislative

actions and educational reforms. Results showed that 70% of the traits assigned by speech clinicians to people who stutter were negative, 24% were positive, and 6% were neutral. In addition, 88% of the adjectives were identical for children, adults, males, and females who stutter, and 93% of the adjectives were concerned with personality characteristics.

Many aspects of these findings are very similar to results obtained from previous studies (Horsley and Fitzgibbon, 1987; Silverman, 1982; Turnbaugh, Guitar, and Hoffman, 1979; Woods and Williams, 1971, 1976; and Yairi and Williams, 1970) thus leading Lass et al. (1989) to conclude:

Perceptions and stereotypes held by speech-language pathologists concerning stutterers have remained relatively unchanged over the past two decades, despite the passage more than 10 years ago of federal legislation aimed at providing equal educational opportunities for the handicapped as well as increased educational requirements and upgrading of certification requirements for speech-language pathologists. (p.133)

Stereotypes of People Who Stutter: Teachers

Five studies on teacher attitudes toward stuttering and people who stutter have been done since 1976. Woods and Williams (1976) found that a group of 20 elementary school teachers, using 25 semantic differential scales, were more

likely than other groups (adults who stutter, parents of children who stutter, parents of children with nonstuttering speech problems, parents of normally speaking children, public-school speech clinicians, and college students) to perceive the hypothetical construct of "a boy who stutters" as different from "a boy who does not stutter". Specific differences, however, were not elaborated. Woods (1978) replicated the Woods and Williams (1976) study using 16 classroom teachers and 11 speech clinicians and found that people who stutter were stereotyped as more "nonassertive, tense, insecure, and afraid to talk" than individuals who do not stutter. Classroom teachers consistently rated the boy who stutters less favorably than did speech clinicians.

Yeakle and Cooper (1986) developed the Teachers' Perceptions of Stuttering Inventory to assess the attitudes of 521 city school teachers in Tuscaloosa, Alabama. Results showed that 56% of the respondents felt that stuttering is caused by an underlying psychological problem, and 42% felt that people who stutter possess a stereotyped personality described as quiet, shy, and nonverbal. Teachers who had taken a course in communication disorders, however, were less likely to believe that stuttering is caused by a psychological problem. No significant correlations were found between teachers attitudes and years of experience teaching.

Two additional studies have focused on the relationship between the gender and stereotype of the person who stutters. Horsley and FitzGibbon (1987) found that graduate students in a teacher-training course tended to hold a strong negative stereotype of children who stutter, especially of school-age girls, while experienced teachers were "more moderate in their judgments of girls who stutter than they were of boys" (p.30). In contrast, Silverman and Van Opens (1980) found that kindergarten through sixth grade classroom teachers were more likely to refer boys than girls for speech-language therapy who presented the disorder of stuttering. This finding suggests that stuttering in boys is more likely to be viewed as undesirable than stuttering in girls. Woods and Williams (1976, p.277), for example, speculate that "the academic retardation which is reported for stuttering boys of normal intelligence (Williams, Melrose, and Woods, 1969) could be partially due to classroom teachers' stereotyped expectations" of boys who stutter.

Stereotypes of People Who Stutter: Parents

Woods and Williams (1976) found that parents of stuttering children, parents of children with nonstuttering speech problems, and parents of normally speaking children all have negative stereotypes of men and boys who stutter. Crowe and Walton (1977) found that parents of children who

stutter possess more undesirable attitudes toward stuttering than do parents of children who do not stutter. Parents of nonstuttering children were found to be more knowledgeable about stuttering than parents with children who stutter. Fowlie and Cooper (1978) found that compared to mothers of nonstuttering boys, mothers of boys who stutter described their children as more anxious, introverted, fearful, sensitive, withdrawn, and insecure. Although no studies addressing fathers' perceptions of their children who stutter could be located, Burley and Renaldi (1986) found that males tend to rate people who stutter less favorably on personality dimensions than female raters.

The Workplace: Stereotypes of People Who Stutter

Two published studies address stereotypes of people who stutter in the workplace. One study (Hurst and Cooper, 1983) found that although employers rejected the notion that stuttering interferes with job performance, it was felt that stuttering decreases employability and interferes with promotion possibilities. A second study (Silverman and Paynter, 1990) found that people who stutter are regarded as less competent than nonstutterers in the same occupations, and that people who stutter will be regarded as more incompetent in occupations requiring frequent verbal interaction with the general public. Consistent with these

views are findings that show stuttering influences listeners' evaluations of a speaker's competence (Duffy, Hunt, and Giolas, 1975).

Everyday life Experiences of People Who Stutter

Despite the large number of negative stereotypes and misunderstandings about people who stutter, there has been very little psychological research geared toward clarifying what it means to live with a stutter. In 1934, a study of 80 people who stutter, ranging in age from 7 to 42, found that "stuttering becomes, with increasing age, a greater and greater burden with which non-stutterers do not have to contend" (Johnson, p.419). In a study of how people who stutter cope with their stuttering, Petrunik and Shearing (1983) found:

they are concerned both with preserving an acceptable identity and with preserving orderly interaction so that they can get on with the business of living...Stutterers sometimes find themselves in situations in which it is not possible to simultaneously achieve both these objectives and thus are required to choose between them. (p.136)

Studies of communication attitudes show that people who stutter tend to have less favorable attitudes toward speaking (Quesal & Shank, 1978), speak less, and avoid speaking more than do others (Brown & Hull, 1942; Trotter &

Bergmann, 1957). In 1984, Manning, Daily, and Wallace (1984) studied 29 people who stutter, aged 52 to 82 years, and found that most experienced their stuttering as less handicapping than it had been earlier in their lives.

Most first-person descriptions of living with a stutter have been gained through experiences in speech therapy clinics (Bloodstein, 1987), and these reports are not available in the published literature. There have been, however, a few autobiographical and experiential accounts published over the years (e.g., Carlisle, 1985; Johnson, 1930; Murray, 1980; Purohit, 1947; Wedberg, 1954). Carlisle (1985), for example, describes having a stutter as like "living with an albatross around your neck" (p.152), and Murray (1980) says that "almost everybody I had known and everything that had happened to me had told me that my handicap was something to be ashamed of" (p.91). Overall, the sparse autobiographical and experiential literature appears to suggest that stuttering significantly affects the everyday lives of people who stutter such as in relations with children (Murphy, 1992; Trowbridge, 1992) and parents (Taylor, 1992), attending the cinema (Zimmerman, 1992), employment (Lingrey, 1992), and job discrimination (Scarborough, 1992).

Experiences of living with a stutter are issues of considerable importance in the speech therapy clinic (Murphy, 1977; Van Riper, 1973). Yet research has moved

toward investigations of the physiological aspects of stuttering and has neglected the issues with which people who stutter must deal in everyday life such as work, education, family, and other social relationships (Quesal, 1989). Compounding the problem is the fact that attitudes of speech and language clinicians toward people who stutter are important clinical variables influencing the interpersonal relationship between clinician and client, and the clinician's management of therapy (Cooper, 1965; Kroll & O'Keefe, 1990; Murphy, 1977). The above review of research on stereotypes, however, shows that speech clinicians tend to have negative attitudes toward people who stutter, and similar trends seem to characterize the domains of education, employment, and family. The goal of the present study is to interview people who stutter about their everyday life experiences in order to present a more faithful reflection of what it means to live with a stutter.

CHAPTER 2

METHOD

Subjects

All subjects were volunteers attending the annual convention of the National Stuttering Project in Dallas, Texas. The selection of subjects was influenced by two factors. First, as Polkinghorne (1989) has noted, subjects must have experience with the particular topic of research. Second, an important criteria for subject selection in research with people who stutter is the subject's "self-identification" as a "person who stutters" (Alfonso, 1990). The subject population of this study consisted of eight males and four females who considered themselves to be people who stutter. Ages ranged from 23 to 67 years with a mean age of 39. All subjects reported that they had been stuttering since early childhood.

Procedure

Each subject was asked to describe as fully as possible her or his experience of living with a stutter. More specifically, they were asked two questions: first, they were asked to "describe situations or events in everyday life that stand out for you as a person who stutters"; second, they were asked to describe their experiences of

attending the National Stuttering Project Convention. The second question was asked to establish a baseline against which answers to the first question could be contrasted. The rationale was that the National Stuttering Project convention provided a somewhat different context from everyday life in that it constituted a community of people who stutter. The interviews were conducted in a dialogal manner.

All interviews were audio-recorded and subsequently transcribed. For several reasons, all stuttering was omitted from the transcriptions. First, the intra- and interobserver agreement for judgments of occurrences of stuttering is quite low (Young, 1984). Second, much of the behavior that constitutes stuttering is nonverbal and therefore was not accessible through audio-recording. Third, given the ambiguity of what constitutes stuttering for the listener, and the inaccessibility of some stuttering phenomena, a coding system for stuttering was not pragmatic.

Analysis of Interviews

The interview transcripts were analyzed using an intuitive/inductive method synthesized from methods originally sketched by Giorgi (1975; 1985) and Colaizzi (1978) and subsequently detailed by Wertz (1983; 1984) in which the researcher's focus moves from specific insights

about the ideographic toward a more general understanding of the nomothetic:

Step 1. Take the Perspective of the Subject

This step entails a simple reading of the interview text in order to become familiar with the experiences described. At this point, no analysis of the data is attempted. Instead, the interview text is read as many times as necessary to gain some sense of how the text coheres as an entirety. When reading the interviews the researcher tries to take the point of view of the subject. This stance is taken in order to attempt to understand what the subject experienced. To access experience in the way it is lived by the subject, the researcher must attempt to set aside any judgments about the objective validity of what is described. For example, if a subject says that "stuttering is worse than almost any other handicap," no attempt is made by the researcher to evaluate the impartial legitimacy of the statement. Rather, the subject's assertion is understood to reveal how the subject experiences living with a stutter.

In addition to suspending judgments about "objective reality", the researcher sets aside any personal opinions or theoretical assumptions that may obstruct empathic connection with the subject's experience. For example, a common stereotype of people who stutter is that they have distorted perceptions of social relationships (Rosenberg and

Curtis, 1954)). The imposition of such an assumption could predetermine what the researcher sees in a given description and result in findings that might not reflect the experience of the subject. By setting aside such an assumption the researcher stays within the sense of what something means for the subject thus avoiding substituting the researcher's outlook for the perspective and experience of the person who stutters.

One way the researcher's opinions and assumptions were made explicit is through a "bracketing interview" in which the researcher described and made explicit his own experience as a person who stutters. A second way of explicating assumptions was through a literature search designed to uncover how people who stutter are portrayed in various domains, both scientific and mundane. For example, Perkins (1990) points out that it is commonly assumed in the field of Speech Pathology that people who stutter have distorted perceptions of their stuttering. The researcher attempts to uncover as many assumptions about the subject of study as possible and subsequently sets them aside before reading the interviews. In addition, previously unrecognized assumptions continue to be made explicit throughout the course of data analysis.

Step 2. Mark Changes in Lived Meaning

The goal of Step 1 is to assume the perspective of the participants and to gain access to a wholistic/intuitive grasp of what they experience or live through as described in their descriptions. Remaining within the empathic attitude established in Step 1, Step 2 involves identifying where the meaning of an experience changes for the participant during the course of experiencing. In this step, the researcher reads through the interview with an eye toward perceiving shifts in meaning. When these changes in meaning are identified they are literally marked or demarcated on the interview transcripts. Each discrete segment of meaning is called a "meaning unit".

The shifts in meaning become apparent when the researcher allows himself to linger with the description. The researcher reads the description very slowly, immerses himself in the description from the subject's standpoint, and dwells upon it. In other words, the researcher lodges himself in the description from the subject's perspective, resides there, and lives the experience in slow motion.

Coupled with lingering and dwelling is a magnification and amplification of details in the described experience. The slowing down of the experience allows the researcher to pay attention to details and nuances of the experience that might otherwise be passed over. An example is the statement that "stuttering is worse than almost any other handicap or

problem". In a quick reading of the statement the researcher might see an estimation and comparison of the disabling nature of stuttering. Stuttering is compared to other handicaps or problems and is experienced as "worse than almost any other". A slower reading that allows for magnification and amplification of details, however, would reveal a more basic finding that stuttering is experienced by the subject as a "handicap or a problem". The following is a section of an interview and subsequent meaning units derived from the interview text:

Stuttering is worse than almost any other handicap or problem because it is something that you don't know when it will happen. Stuttering isn't always there; There are times when a person who stutters is fluent so subsequently the fluent public thinks that stuttering is no big deal because they feel that if a person wants to be fluent then all he or she has to do is to slow down, take your time, don't be nervous, and on, and on and on. It's really not that easy because speech is almost a full-time occupation. Every time you pick up the phone or meet a person you're always having to be confronted with speech and never know if this is going to be a fluent time or a disfluent time.

Meaning Unit 1

Stuttering is worse than almost any other handicap or problem because it is something that you don't know when it will happen.

Meaning Unit 2

Stuttering isn't always there. There are times when a person who stutters is fluent. So subsequently the fluent public thinks that stuttering is no big deal because they feel that if a person wants to be fluent then all he or she has to do is to slow down, take your time, don't be nervous, and on, and on, and on.

Meaning Unit 3

It's really not that easy because speech is almost a full-time occupation. Every time you pick up the phone or meet a person you're always having to be confronted with speech and never know if this is going to be a fluent time or a disfluent time.

Step 3. Organize Meanings into Theme Clusters

Steps 1 and 2 allow the researcher access to the lived experience of the participant and to demarcate when and where the implicit meaning of an experience changes. These meaning units, however, emerge from the participant's naive description, through the researcher's intuitive understanding, and thus remain intuitive, implicit, and naive. Hence they are "lived meanings". The lived meanings have yet to be made explicit by the researcher. The goal of Step 3, therefore, is to render explicit what the participants mean by what they say and then to aggregate meanings into coherent groups.

The lived meanings are explicated by the researcher through a process of reflection. In this process, the researcher dislodges himself from absorption in the participants perspective and subsequently wonders with intense interest what a particular meaning unit and/or set of meaning units is all about. The researcher then gathers meaning units from all of the descriptions into groups that encompass particular, distinct aspects of the experience in question. In practice, this step involves organizing several tentative theme clusters followed by revision,

reorganization, and regrouping until the essence of one particular theme is accurately reflected in the cluster. In other words, each theme is compared to the original interview texts in order to insure that the experience of living with a stutter is faithfully reflected. In each cluster there are different ways in which the theme shows itself. For example, the first theme discussed in the results is "The Burden of Stuttering" and refers to issues related to effort in living with a stutter. This theme showed itself in four ways: 1) struggles with discoordinated speech; 2) efforts in managing interactional order; 3) problems in effectively communicating a message, and 4) uncertainty about when stuttering will happen, howlong it will last, or how it will be responded to by others.

CHAPTER 3

RESULTS

Analysis of interview texts revealed the following four major themes together with their constituent sub-themes:

Theme 1. The Burden of Stuttering:

- Discoordinated Speech
- Managing Interactional Order
- Effective Communication of a Message
- Uncertainty of Stuttering/ Others' Reactions

Theme 2. Living with Difference:

- Standing Out
- Stigma
- Prejudice
- Alienation

Theme 3. Living with Constraints:

- Quality and Quantity of Spoken Expressions
- Education/Employment
- Social Relationships
- Awareness of Possibilities

Theme 4. Negotiating Life:

- Negotiating the Burden
- Negotiating Difference
- Negotiating Constraints
- Forming Communities of People who Stutter

Theme 1. The Burden of Stuttering

Living with a stutter can be experienced as a burden that is present in any context requiring speaking to others (See Example 1). People who stutter may find themselves with discoordinated speech, losing control of interactional order, employing extra effort to communicate a message effectively, and with the occasional uncertainty about when stuttering will happen and others reactions to it. Making one's way in the world may require extra labor. Indeed, living with a stutter has been variously described as "a struggle", "a battle", "a challenge", and "a full-time occupation". One subject said that "I have to struggle harder than most people."

Example 1

There's a lot of extra burden upon us, and stuttering just doesn't go away. It doesn't go on vacation. You can't just take off somewhere and leave your stuttering behind. It's with you everyday. It's with you in social situations, it's with you in a job, when applying to jobs, when you're in school, when you're applying to schools, when you're with friends, when you're with acquaintances, strangers, relatives, anyone in your life, when you're trying to order something, when you just want to talk with someone, when you want to use the phone. Communication enters so much of our lives and every time there is communication by a person who stutters there is a bit of extra baggage that a person who stutters carries...It doesn't matter how you are dealing with it, even if you are able to control it and are temporarily fluent, your stuttering is still there...It's a constant burden to carry.

Discoordinated Speech. For people who stutter, the act of speaking is experienced as necessitating extended exertion. People who stutter sometimes find themselves without the motor coordination required to speak their

intended expression. This discoordination can range from a difficulty saying certain sounds or words (Example 1) to a nearly complete disruption of the motor capacity for speech (Examples 2, 3 & 4). It is described by participants as "tension", "involuntary spasms", "seizures" or "losing control of speech".

Example 1

The second name starts with a B. I'm not exactly sure what the linguists call it, but it's a problem getting the B sounds out...Sometimes I can get through it with no problem. Most of the time...I have a hell of a time getting out the second name.

Example 2

I went into one of these contortion...that lasted probably fifty seconds at least, with head jerks and all...I was helpless....I didn't have control and I felt things were out of hand.

Example 3

Until you can get your controls back around you, you feel lost. You feel like you're washed out to sea. You've got no control. You're washed out to sea. You're floating there, but the sea is taking you. You're not controlling where you're going. That's what it feels like.

Example 4

Part of it is the feeling of totally being out of control. ...I think that lack of control is worse than the actual physical symptoms themselves. I think most of us would like to think we are in control at least part of the time, but when you're in a block like that, there's really no illusion...you really don't have control. That can be a pretty frightening and frustrating thing.

Managing Interactional Order. People who stutter experience the need to exert extra effort when managing interactional order between themselves and others. A particular problem is the question of speaker status. Stuttering is experienced as relegating an individual to a

lesser status in the eyes of others (Examples 1). For other individuals, stuttering is experienced as exacerbating an already degraded position (Example 2). Some people who stutter are not accorded proper competency or authority (Example 3). One woman who stutters described being subjected to others' condescension and scorn (Example 4). Correspondingly, stuttering sometimes disallows the claiming of one's rightful or desired status. (Examples 5 & 6). Due to such disempowered status, people who stutter are sometimes not taken as seriously as others. As one subject described it, "the ability to communicate verbally is one of the hallmarks of being a human being so that when you're not able to do that as well it almost makes you less of a person." Another subject said: "you really feel like a second class citizen". As such, for some people who stutter, there is the feeling of exertion in keeping or acquiring a certain status: "I expend a great deal of energy being out there, trying to be bright, trying to be intelligent, trying to be nice. I expend a lot more energy than most people feel that they have to...I'm out there pushing."

Example 1

Some years ago I was at a party, and there was a woman I wanted to meet. I walked up to her, tried to introduce myself...The woman looked at me...and said "do you have a disease or something or are you just a nervous person?"...It was quite a devastating experience.

Example 2

I'm not sure if anyone's talked to you about what it is like to be a woman who stutters...Women are not taken as seriously as men by some people...There are people in the world who don't take what a woman has to say with the same weight that they might take what a man has to say...In terms of stuttering, it really becomes another area of "inadequacy" in the eyes of many people. It's another area in which I as a human being might fall short.

Example 3

Other instructors were looking at you like you weren't all there, none of your oars even came close to the water, and this type of thing. The students...would look at you like, well, I'm not too sure about this guy...After each training session, we would get a critique from the students...Some of them went into really great depth as to what I should do: dig ditches, drive a truck, all this kind of stuff.

Example 4

The protest [of the movie A Fish Called Wanda]...was easier in [city 1]...The other cinema which we protested was much less willing to hear our story, and we got mocked by some people...My reaction to the [city 1] situation was I was certainly glad the people were interested in what we had to say. At the same time, I was afraid that they might be taking pity. This sort of guilt trip, you know?...Have you ever heard of "white middle class guilt for the poor"? I was afraid that they were over-reacting. I didn't want to be patronized...What's the baggage that you folks are bringing to this, fluent guilt? You know, don't patronize me, we'll state our case, either agree or disagree, but we'll do the work...At the other cinema, that was harder in terms of being ignored and not being taken seriously...I had the sense that it was a slice of the real world. I wasn't being patronized, heaven knows...Basically, they thought we were making too much of it...There were a few people there who thought it was fun to tease people who stutter because we are obviously really messed up...It was miserable being laughed at.

Example 5

I remember learning in school that trying to defend myself [from others' ridicule of stuttering] was often just a way of digging myself in deeper, because when I tried to defend myself I would stutter more, and so it would give them...something additional to laugh about.

Examples 6

It's the fact that I can't express myself as assertively. I feel when I stutter I can't be assertive...It's like the rug is pulled out from under my feet.

Along with the issue of speaker status, there is a pace to the dialogue in the fluent speaking world that may not be conducive to effective communication for people who stutter. One subject pointed out: "I have a lot of trouble with people who are fast, rapid in their speech...For me to practice skills that make my communication more comfortable for me, there's a slower pace involved." Given the different rate of dialogue that is sometimes needed, people who stutter may lose the listener's attention (Example 1), or be asked to write down their message rather than say it (Example 2). A very common situation is when listeners interrupt and try to complete the speaker's statement instead of waiting for the person to speak for him or herself. Listeners often are very wrong in their anticipations of what the person who stutters is saying and such interruptions complicate the speaking situation because the person who stutters must now undo the listener's mistaken conclusions as well as express the message originally intended (Example 3). On this basis, speaking, which was already a struggle, becomes more so.

Example 1

If they're looking off somewhere or they're not paying attention, it makes the frustration multiply. It makes the block or the problem you're currently having all that much worse by the fact that now you're having to contend with their inability to maintain

attention...You just want to reach out there sometimes and grab them by the tie and say look, pay attention, I'm speaking here.

Example 2

I was waiting for the shuttle...The driver came along and asked me where I wanted to go...The words seemed so difficult to say and I just couldn't get anything out. Meanwhile, there were other passengers, and they were getting on, and the driver was asking them where they wanted to go, and people were in a hurry, and the driver wanted to get started, and the other passengers were on, and I still was standing in front trying to tell the driver where I wanted to go. One of the passengers suggested please be so kind as to write this out, and make it all easier on us.

Example 3

I always found it very frustrating. I'd be trying to say something and somebody would go on and say it...and they'd finish it wrong, and then you had to either let that wrong concept go or you had to go back and try and say it one more time. They could have just not even tried, and let me go on, and it might take longer but at least I would have done it myself.

Effective Communication of a Message. Another way in which the burden of stuttering shows itself is in the actual communication of a spoken message. At times, there may be some concern about the extent to which a spoken message has been effectively communicated. In many instances the message is successfully communicated despite stuttering (Example 1). In other situations, the listener may not comprehend the communication thus subjecting the person who stutters to misunderstanding. Extra effort must be made on the part of the person who stutters to assure the listener's comprehension (Example 2). Another circumstance is when the person who stutters is left wondering whether the message received was the message communicated (Example 3).

Example 1

I had to interview a group of athletes. I stuttered like crazy, it was every syllable: m-m-m-m-m-my n-n-n-n-name, that's how I was doing it. Still, because my repetitions were fast enough, people could get the sentence after I was done.

Example 2

I was taking a taxi from the bus station to my dorm...The fare was six dollars so I figured I would give him seven...I gave the driver a ten and I tried to indicate to him that I wanted him to give me three dollars in change...I couldn't get anywhere near the "th". He began to write out a receipt for the ten dollars. He figured I wanted him to have the whole thing, but I continued to stay in the cab until I was able to get out something approximating "three". I didn't know if he understood it or not so I tried to motion in any way I could, holding up three fingers. Well, he finally understood what I said. But, you know, this kind of thing has been typical...My feeling was I was not going to surrender my ten dollars to him.

Example 3

I was ordering by phone and trying to identify my last name to a chicken and ribs place....I tried and tried, I finally blurted out something, some messed up version of the name, and then I quickly began to spell it. The person on the other end of the line stopped me and said "that's O.K., I've got it". I didn't know what name she got.

Uncertainty. Compounding the burden for some subjects is a sense of uncertainty about when stuttering will happen, how long it will last, and reactions to it. While some people report having fluent days and dysfluent days as well as extended periods of fluency and dysfluency that may run in cycles, other people find it difficult to predict when stuttering will happen (Examples 1 & 2). Likewise, people who stutter do not know when they will encounter problematic reactions from others. This uncertainty can seem especially thematic in situations concerning new acquaintances

(Examples 2 & 3). The person who stutters does not know the extent and depth of the others' understanding of, attitudes toward, and/or experiences with stuttering and people who stutter such that potential or actual problems of interaction order can become very salient (Examples 3 & 4).

Example 1

I would say that stuttering is worse than almost any other handicap or problem because it is something that you don't know when it will happen...Every time you pick up the phone or meet a person, you're always having to be confronted with speech, and never know if this is going to be a fluent time or a disfluent time.

Example 2

I guess I have a general idea about whether I will do well or not well. That's what I know beforehand. If I sense I'm not going to do well, I really don't know how badly...it's going to wind up. It might be that I may have just some short blocks, and some short severe blocks but still be able to communicate my message, or they might be really long, powerful blocks and I may find it very difficult to communicate what my message is...It makes such situations somewhat of a mystery before they take place, and I can only hope...that the situation is not going to be a bad one...This uncertainty really unnerves me. I like to be in command of what's going on.

Example 3

It's an experience full of uncertainty...as to how the listener will react...People who stutter don't know what to expect when they start to stutter in front of a stranger.

Example 4

It's a little scary, you never know the way that people are. I gave a presentation back in January to the...vice president of engineering, and he turned out to be the nicest guy that you could ever want to meet. Before the meeting I was really up-tight...but it turned out he was a down to earth type of guy. The speech impediment didn't bother him.

Theme 2. Living with Difference

There is a sense of differentness that comes with being a person who stutters. As one subject said, "to be a person who stutters means to recognize that you are different". Another subject said "it's extremely tough because you are having to confront the fact that you don't talk like a normal person talks, and you're always confronting speech". This difference is experienced in terms of standing out in a crowd, stigma, prejudice, and alienation.

Standing Out. Indeed, people who stutter recognize the dissimilarity between their speech and the speech of fluent speakers (Example 1). One difference, previously mentioned in Theme 1, concerns the tempo of stuttered speech. People who stutter tend to speak at a pace that sometimes disrupts the taken-for granted rhythm of fluent dialogue thus making the person who stutters stand out as different (Example 2).

Example 1

It's a different species of speech. A type of speech that is abnormal. It is a classification of speech that is not within the normal limit.

Example 2

Its a group of words that everybody knows you should know, and you don't get them out on time and on schedule. It makes you the odd ball in the group.

The different qualities of stuttered speech are in the world for others to see and hear (Example 1), and the sense of differentness that people who stutter experience is reflected in their relations with others: "I became aware, somewhere along, that society reacted [to stuttering], and

then you've got the fat in the fire with the social thing". Part of the "social thing" is that people who stutter are sometimes responded to and treated in ways unlike those accorded fluent speakers (Example 2). This difference can be apparent in others' nonverbal behavior as well (Example 3).

Example 1

In a way, it's a unique thing about us...It's out there...People can see it and here it....It's apparent and it's really prominent in communication for people who stutter.

Example 2

When I got through ordering my hot pastrami sandwich the owner said "may God bless you"...He hadn't blessed anyone else in line, and I was thinking that was the only time in my life that I got blessed for ordering a pastrami sandwich...I guess on one hand I felt a little bit of gratitude for this little outpouring of sympathy, however ridiculously it was expressed. On the other hand, I like to receive the same treatment as everybody else. I realized no one else had been blessed.

Example 3

They don't come right out and tell you...They look off into a corner somewhere while you're speaking to them. There's a lot of people out there like that...They don't overtly come out and say, hey, you know, you got a problem, go get it worked on. But you can tell by the way that they act, basically looking away from you, they got a problem with it.

Stigma. The previous example shows that certain people react to stuttering as if it were a "problem". Part of the social problem of stuttering is that it may detract from the perceived character, status, or reputation of the person who stutters. It has already been noted in regard to Theme 1 that people who stutter sometimes experience a loss of status in the eyes of others and, indeed, stuttering can be

perceived and experienced as a stigma (Examples 1 & 2).

Stuttering is sometimes referred to as a "blemish" or "flaw" that tarnishes the person who stutters.

Example 1

I was punished for it by my mother...To talk about something that makes my mom punish me isn't good. It isn't a good thing. It's something I ought to not have, so it must be something bad, some type of blemish.

Example 2

You feel like you're the hunchback of Notre Dame. You're the Phantom of the Opera. You're the elephant man. You feel like you're one of a kind.

One way that the stigma of stuttering shows itself is in terms of negative media portrayals of people who stutter, and the reactions of other people to such portrayals (Example 3). These unflattering media portrayals of people who stutter invade the interpersonal domain, leaving the person who stutters with a self-conscious sense that others may or will view them through the light of that stigma (Example 4). In addition to being a flaw that disgraces people who stutter, stuttering can also be experienced as stigmatizing those who associate with individuals who stutter (Examples 5, 6 & 7). This stigma-by-association turns back onto the person who stutters thereby exacerbating the negative sense of differentness.

Example 3

The audience began to laugh really, really hard...They were laughing at the difficulty that the person who stutters was having in speaking. To hear a theater full of people laughing at...a stereotype of a person who stutters as a stupid clown, I think that was what was difficult.

Example 4

After the movie [A Fish Called Wanda], I happened to see another student from [college] there, and when I went over to her I was very much aware of the fact that here I was going to stutter. I might stutter after this movie with this character being mocked for stuttering...Here I am about to prove it all. Here I am about to expose that I am like this fool in the movie. That was hard.

Example 5

My family thought it was shameful. They were embarrassed by it, and so I felt like I was flawed or somehow tarnished...Part of my speech problem was a big, big, problem in their lives, too. They couldn't have this perfect child if I stuttered. They would have to speak for me, in certain occasions anyway, if I would struggle and block in front of their friends. Image was so important to my family.

Example 6

The fact that I stutter has added to my sort of being second best, to being obviously flawed...I have this speech impediment. I was, therefore, less than perfect. I couldn't be pushed out ahead to make the family proud, you know, go out dear and tell all those people about all those marvelous things you've done. I couldn't be pushed that way because I'd go out there and I'd begin stuttering.

Example 7

I think the hardest part was the feeling of insecurity on the part of the other instructors. They were insecure that I was there; I was a stutterer. I don't know whether it made them feel less skillful as an instructor or what. If a guy can stutter and do this kind of stuff, why hell, what are we doing here? We aren't that great then.

Prejudice. In addition to stigma or flaw, the sense of being different shows itself in issues of prejudice.

Stuttering renders the person who stutters subject to negative evaluations of others. Other people sometimes form opinions and make judgments about a person who stutters, based on negative attitudes about stuttering, that extend to

other aspects of the person. One way that prejudice shows itself is when negative judgments and opinions are made before all the facts are known about the phenomenon of stuttering or the person who stutters (Example 1 & 2). Sometimes these negative opinions can be softened through extended interaction with others (Example 3). At other times, however, prejudices remain despite the best efforts on the part of the person who stutters to change them. These negative judgments and opinions are held in disregard of the facts (Example 4).

Example 1

I've often heard people say that our thoughts are faster than our mouths or vice versa, those kinds of things. I get really angry when I hear people who think they know a lot about our problem. They think it's a psychological problem...People are very ignorant of stuttering.

Example 2

If a person doesn't know I stutter they might think I'm on drugs, might think I'm retarded, might think I'm just withdrawn or antisocial, or any other numerous problems.

Example 3

At work, at home, on the telephone, you are constantly having to be concerned with how you talk and how people are hearing you because initially you are judged by how you come across when you speak. It is extremely hard in the real world...Initially they think that I'm slow or dumb. They think that they can sort of disregard me, which isn't the case at all. Generally, though, once people have time to know me then they find out that I am a fairly smart person and also a fairly confident person as well. Their perceptions of me tend to change after a while.

Example 4

In their minds...was the assumption or their belief, which I never was able to shake, that I was a loner, that I was unfriendly. They always, no matter how hard I tried to break that belief, I think they always tried

to carry that belief in their heads. Going back just a few years before I started doing clinical work, they told me outright they're afraid of my working with children because, you know, the fact that they saw me as being unable to interact with other people. In my actual clinical work, my clients all made great progress...and yet this fear of my being with children dominated a lot of the clinical faculty.

Another type of experienced prejudice is the suspicion of others; that is stuttering arouses suspicion in others and the person who stutters is treated as suspect (Example 5). A final form of prejudice is the other's intolerance of stuttering and people who stutter. Some people who stutter experience others and society as unwilling to accommodate or assimilate their differentness (Examples 6 & 7).

Example 5

I had to go to work and I wasn't able to...I had to report that I couldn't make it. People at work don't know that I stutter because I don't stutter all the time....You have to call right away because if you don't that's being irresponsible. I ended up calling thirty minutes later and they asked why I didn't call before. What am I supposed to say? They don't know I stutter because I don't always stutter, and if I tell them I do they're like, what? How come we never heard you stutter? What is this? What do you mean you stutter? They're probably thinking that I'm lying, that I'm stuttering because I'm nervous because what I'm telling them is a lie, you know, over the phone, I'm going to be late, and they have reasons to believe that because I don't always stutter. When that happens it's the worst...These people are perceiving you as irresponsible.

Example 6

I think stuttering is not regarded seriously by the public as a major disability...I think much of the public is under the impression that if a person who stutters just thought a little bit more about what they were saying, or slowed down a bit, or just made some minor adjustments, or used a little bit of will power they would be fluent...They come to a conclusion that a

person is just not applying themselves to fix up their own speech, and if they really applied themselves they could do so.

Example 7

Regarding stuttering, there just isn't this general feeling of public perception of this as a major disability and people who stutter to be seriously respected. It's one of the few disabilities...where it is still acceptable for a person to laugh at it...or be amused by it...We got this caricature in A Fish Called Wanda where I believe stuttering was there as...a vehicle for some extra laughs. I think that the mass media has always looked at stuttering as something amusing; Porky Pig, for example.

Alienation. Along with stigma and prejudice, people who stutter sometimes experience a sense of alienation from others and themselves. Part of this alienation concerns a sense of isolation from a larger community. On one hand, some individuals who stutter experience themselves as separate from the fluent speaking community. One subject said that "normally, I'm a very tiny minority in a world full of fluent people". Another subject said "you're one of one half percent of the population, and you're definitely the minority". On the other hand, some subjects, given that individuals who stutter are so few in the general population, have found themselves without a community of people who are like them (Example 1). Being without a community of can leave people who stutter feeling alone and unsupported (Example 2).

Example 1

Stutterers are for the most part isolated people. I don't mean they're not around other people, but they don't, when they're young especially, they don't realize that there are other people out there who have exactly the same problem...It feels lonely.

Example 2

I had no one to share these feelings with...I was literally alone....I was very lonely. I had people around me...but it didn't matter. I was still alone because nobody knew how I felt....But sometimes I'm just tired because you're in an environment that really doesn't support you.

Another way alienation shows itself is in the feeling that the fluent speaking community does not understand what it is like to stutter in a fluent speaking world: "you go out into the real world and no matter how much people say I understand, I understand, if they don't stutter, they don't understand". Part of the lack of understanding stems from the inability of fluent speakers to recognize that stuttering negatively affects the lives of people who stutter (Examples 1, 2 & 3). A particularly frustrating experience for people who stutter is when fluent speakers naively try to minimize the difference between themselves and the person who stutters by suggesting that stuttering is not a significant issue because "it happens to everybody". In this case, fluent speakers are experienced as underrating or diminishing the negative impact that stuttering has on the lives of people who stutter (Example 4).

Example 1

It's a constant burden to carry, and I don't think most fluent people realize the extent of this burden or how much it deeply affects our lives in all their aspects, both business and pleasure.

Example 2

I'm bilingual...My dad would ask me to call a place, to interpret for him, to call an insurance company or something like that. For me, it used to be the hardest thing to do. I would not avoid it, but I would call an hour after he asked me to. Sometimes he needed the call

sooner so he would ask me "did you make the call yet?" I said I haven't yet and he got really upset because it was an important call. See, my parents never saw my speech impediment as a problem especially because I don't always stutter. They didn't understand. He thought I was being irresponsible. He thought, well O.K., I can't even count on my daughter. She must not care. But that's not true...People hang up on me.

Example 3

I was asking somebody something and he began making fun of me. I think I told him if he didn't stop making fun of me I would wring his neck...I think he missed the whole thing. I think he missed the fact that I was angry. He missed the fact that what I was doing is called stuttering. I think he just missed the whole thing and probably would still make fun of my stuttering should I ever have the misfortune to talk with him again.

Example 4

It's very frustrating...They don't understand...They say "oh, but everybody stutters, don't worry about it. It's o.k., I stutter sometimes"...I'm like, yes, but yours is a normal disfluency. Everybody does have normal disfluencies...It's different when it's beyond the normal, when you can't say your name, when you can't say certain information over the phone, or whatever that's really important to communicate with your listener. That's when it's a problem, and that's when it's frustrating. They try to make you believe that it's o.k., that it happens to everybody...It really is not o.k. It's taking a lot from me, and it's putting me in a situation where...it could endanger my job or my education.

Some people who stutter speak of a kind of self alienation in which stuttering is experienced as an unacceptable part or aspect of themselves. Stuttering is something they do not want to have and a person who stutters is not somebody they want to be (Examples 1, 2, & 3). Feelings of shame may accompany this sense of alienation.

Example 1

I wasn't very fond of myself. I didn't like who I was.

Example 2

Way back it [being a person who stutters] meant a horrible thing. It meant a false image, it meant hating myself.

Example 3

I was somebody I didn't want to be, having an affliction I didn't want to have.

Theme 3. Living with Constraints

People who stutter can experience a sense of restriction imposed by stuttering. Stuttering can be experienced as limiting the extent to which an individual is able to participate in everyday life. One participant said that "it's like being in prison", while another said that "it's almost like a feeling of being trapped". As such, people who stutter sometimes feel confined or obstructed in everyday living by their stuttering (Examples 1, 2, & 3).

Example 1

I always felt that my stuttering was certainly hindering me from doing anything that I wanted to do.

Example 2

It's difficult to sit on the outside looking in, and that's essentially what you're doing. You're sitting on the outside...You're on the outside looking in just like, I would imagine...what paraplegics feel when they're at a doorway and they can't get through it. You're on the outside looking in. It's depressing.

Example 3

I would say that stuttering has been a factor that has limited me in what I felt I could do.

Spoken Expressions. One particular restriction concerns the extent to which people who stutter experience stuttering as limiting the quality and quantity of their spoken expressions. Indeed, instances of stuttering are

commonly described as "blocks", and stuttering is experienced as an obstacle through or around which the individual must traverse. Stuttering can be experienced as frustrating because it may prevent the prompt expression of thoughts and ideas. Although a person may have much to contribute to dialogue, stuttering is experienced as minimizing the contribution (Example 1).

Example 1

I've always been quite bright and had all these things I wanted to say but just couldn't readily say them. To have all these things bottled up inside that I really wanted to say but I just couldn't, that was a source of great frustration.

The presence of stuttering also may require the person who stutters to present simplified versions of their thoughts and ideas in order to facilitate their expression. The result is that one's spoken expressions may not reflect the complexity and detail that might otherwise be expressed (Examples 2 & 3). A further limitation is when stuttering prevents expression of the intended message and something entirely different is said in order to get through the speaking situation. One possible consequence is that desires are changed or left unfulfilled (Example 4).

Example 2

Everything I wanted to say was crafted in a way I could say it. I used to pick and choose words and chisel down any eloquent thought I had into something I could say...What would come out would be so different than what I created in my mind.

Example 3

I won't explain something as fully as I might have if I had been more fluent...it's a more abbreviated form.

Example 4

She wanted a strawberry shake and I wanted a vanilla shake...I started stuttering, and tripping on my words and blocking. I ended up just struggling to get out "two chocolate shakes". I went out to the car, giving her a chocolate shake that she didn't want, me drinking a chocolate shake I really didn't want, but that's the best I could do.

Education/Employment. People who stutter are aware of potential and actual limits on their education and employment imposed by stuttering and the attitudes of other people toward it. One concern is that particular job and educational domains are out of bounds; for example that some occupations are beyond their reach due to their speech or the reactions of other people to it (Example 1). A second concern is that employers will not hire an individual if he or she stutters, or that finding employment will be unusually difficult. The feeling is that stuttering may render the person as less competent in the eyes of others (Examples 2, 3, & 4). A third concern is that individuals who stutter will be relegated to employment that does not allow them to fulfill their potential; the sense sometimes is that one has virtually no future (Example 5). Some people who stutter feel that their stuttering prevents them from doing their job as well as they might otherwise. Although they perform their job competently, some participants report feeling that stuttering gets in the way of optimal performance (Example 6). Other people who stutter are faced with being prevented from completing or

fulfilling their educational or employment goals due to prejudice and discrimination (Example 7).

Example 1

If I were a CBS newscaster in New York...I believe the phone would be ringing off the hook...I think there are certain things we could never do.

Example 2

It would be very difficult to find a good job if I wasn't able to communicate better.

Example 3

If I talk like that I'll never find another job. Just how am I going to get through life?

Example 4

People won't hire me because I stutter.

Example 5

During my college years, I took a vocational test. A week later I went for an interview to assess the results. I was told that teaching was, by far, the profession for which I seemed best suited. In second and third places were some other types of jobs...I forget them now, years later. As the interviewer put the papers aside, he asked me one or two direct questions. I stuttered severely...in my reply. Startled, he told me I could never engage in any of these three professions because of my stuttering and that teaching, the number one on the list, would be absolutely impossible for me to consider. Shocked and disheartened, I haltingly asked what he thought I could do. He replied, "Well, er, I supposed you might be able to work at the post office, however, most certainly not at the front window where you would have to talk." This was an insultingly bitter blow to me! I thought this thing was shutting off my life, it was snuffing out everything.

Example 6

It bothers me that I can't say what I want to say right out...it's annoying not to be able to go up to someone and say I need to borrow the fork lift...I wish I could just do my job better.

Example 7

I have experienced discrimination throughout my life, because I stutter, in various aspects of employment and recently education...The school I am at...denied me the right to complete my clinical degree in speech

pathology. I have an excellent record there...It was really obvious that they...didn't like the fact that someone who had a speech disorder was giving therapy lessons to their clients. They are much more comfortable with stuttering as something to be treated in their clinic rather than as something which one of their clinicians or students has.

Social Relationships. The above examples show that people who stutter are aware of limits on their potential for employment because of others' feelings about stuttering and those who stutter. Stuttering and the feelings of other people about it may also limit the extent and kind of relationship the person who stutters has with fluent speaking others. Theme 1, for example, reveals that people who stutter may encounter difficulty managing interactional order and lose status in the eyes of other people due to their stuttering. Theme 2 reveals that stuttering may stigmatize individuals and render them subject to prejudice and alienation, all of which delimit the extent and kind of relationships a person who stutters may have with certain others. Limits on one's relationships with others can range from problems in establishing new relationships to the keeping of established ones (Examples 1 & 2).

Example 1

It was really hard to make new friends...I'm outgoing and I'm friendly, but I didn't have my speech under control. I'd try to make a friend and I couldn't call them.

Example 2

Stuttering was very instrumental in my divorce...It was an underlying cause of the problems we had in our marriage...She didn't want to deal with a person who was a dud. My stuttering made me a dud.

Awareness of Possibilities. Although stuttering may be experienced as hindering one's everyday life, it can also be experienced as facilitating favorable growth. The everyday life experiences of people who stutter may provide the person who stutters with an awareness of themselves, others, and life that they might not have experienced otherwise. One subject, for example, spoke of the courage required to face the negative impact of living with a stutter, and the discovery and appreciation of her other qualities (Example 1). Other subjects spoke of gaining empathy for others' suffering (Example 2), insights about group interaction (Example 3), and awareness of nonverbal behavior (Example 4). Overall, there is a recognition that stuttering has both limited and contributed to one's life (Example 5 & 6).

Example 1

Being a stutterer means you have a lot of guts and courage to face the world because it's a very humiliating experience, it's a very fearful experience, it's really hard to deal with, it's very lonely, it's very depressing, but when you work on it you get a lot of positive experiences. You learn to value the beauty of life, you're a more sensitive person, you appreciate all your other gifts. You appreciate the gift of walking, the gift of seeing, the gift of hearing because you know what it is to be impaired with your speech so you appreciate everything else, and you cherish every moment of your life. There are a lot of negative things to it, but you can see it in another way.

Example 2

It's made me very sensitive to the suffering of others. I can perceive when a remark can be hurtful, or how a casual remark can be hurtful to someone. Just in

conversations with other people, I'm sensitive to the inflection of their voices and the meaning of their words.

Example 3

I wasn't as verbally active, so I paid more attention to what was going on around me...I was always aware of the dynamics of people, in groups, in interactions...What really became a part of me was being able to be insightful or intuitive about people.

Example 4

Stuttering has taught me a lot of things...To have empathy for people, to be able to look into a person's face and tell pretty much what that person is thinking, how he's going to act, to be able to read body language, to be able to read facial expression, to be able to think on your feet, to be able to couch the presentation in terms that people will accept. I think if I hadn't been a stutterer I would have been slow in picking that up

Example 5

I think it's led me to be perceptive about life...Certainly to see things in a way which I wouldn't have seen otherwise.

Example 6

I feel that my stuttering, in my early years, was a terrible handicap, but I think on the basis of that...I learned a lot. I learned a lot and in so doing I think I shaped my whole life

Theme 4. Negotiating Life

Living with a stutter requires a lot of negotiation; on one hand, the person is concerned with how to get through a moment of stuttering, on the other hand, the person who stutters is concerned with getting through life in a fluent speaking world. Subjects talk about adjusting, adapting, coping, reconciling, dealing with, coming to terms with, and accepting life with a stutter. People who stutter describe

negotiating their struggle, difference, and limits, and forming communities of people who stutter.

Negotiating the Burden. As one subject said, "You are going to live with stuttering for the rest of your life, you might as well get used to it. You might as well learn to work with it." Individuals report having strategies which they attempt to employ in order to "escape", "dodge", "get through", or "minimize" a "block" (a moment of stuttering). Some of these strategies are learned or acquired through speech therapy. One subject described these techniques as "tools...to get me out of the times when I'm really having a problem". Some strategies are acquired through experience such as word substitution and using interjections such as "um" and "ah" while waiting for the moment of stuttering to end (Examples 1, 2 & 3). A frequently mentioned problematic situation is when statements must be said verbatim, such as names and reading from a text. In these situations, people who stutter can not dodge the problematic sounds and words but instead must struggle their way through the statement (Example 3 & 4).

Example 1

Most of the time, I must admit, I go at it like a bull at a gate. I just try and force my way through it.

Example 2

If I'm in a good period, I...have to think about my targets [fluency techniques], my breathing, my onsets, my stretching syllables...If I'm having a very bad day and I'm being disfluent...the second train of thought is how am I going to get through this sentence? Am I going to really block? Can I substitute something?

Can I slide something under another word? All these little tricks going on in my mind. Usually none of them will work.

Example 3

I did a lot of things to get by...As an officer in school I had to present in front of the student body. I knew that if I wrote a speech verbatim I would struggle a lot more if I read. I would just get up there, hold the mike, just ad lib, then I could pick and choose sounds and words, and change the word structure around. I could use gestures. I was very colorful and very flirtatious, just kind of charming and playful. I would never talk to anyone at length because I knew if I did I would start stuttering because it's harder to pick and choose [sounds and words] when people are asking questions and you're getting in an exchange. I couldn't do it as well.

Example 4

Most of the time, tension is built up to the point where I have a hell of a time getting out the second name. After that, everything becomes easier...All the rest of the words can be chosen. I don't have to say exactly this grouping of words.

In addition to the struggle with speech and traversing the moment of stuttering, people who stutter are faced with negotiating interactional order, as well as with effectively communicating a message. Sometimes these challenges lead to compromise; on other occasions there is the sense of accomplishment and empowerment (Examples 1, 2 & 3).

Example 1

When I was in school...I would not answer any questions...More often than not, even though I knew the answer, I would just tell the teacher I don't know, and of course I would get a grade of F...I didn't have to go through the struggle of stuttering but I ended up with a F.

Example 2

I decided it was in the best interests of everyone to give in somewhat so I wrote down where I wanted to go, but deliberately...wrote it in a very sloppy hand writing so he couldn't read it...So therefore I gave myself a second chance. Finally, I was able to say

where I wanted to go as the driver was trying to decipher my hand writing...I just did not want to go down in total defeat.

Example 3

[Protesting the movie A fish Called Wanda] was a struggle on behalf of people who stutter...Our point of view on the movie had to be heard...It was really empowering just to be there. The fact that we were there, doing the best we could, saying what we had to say. To me, that was the most important thing. We got laughed at, we got told to move across the street by the cinema management, but at least we did something...Everyone came through it empowered, feeling like we had control of our lives, or we were trying to take control.

Negotiating Difference. Given the stigmatizing, prejudicial, and alienating nature of the differences defined by stuttering, people who stutter are faced with the issue of what to do about those differences. One way of dealing with the problems posed by their different speech is to minimize the difference. One way to minimize the difference is to hide the stuttering from the listener (Examples 1 & 2). The cognitive strategies used by people who stutter to get through or around periods of disfluency can also be used to hide stuttering or make stuttering less noticeable to others (Example 3). The facade, however, may be a fragile one that may collapse at any time, leaving the person who stutters concerned about being "found out" (Example 4). A second way of hiding stuttering is to just not speak (Example 5). Many people who stutter seek out professional speech therapy with the hope that they might achieve a kind of speech that is more acceptable to the general community. Others, including those who have had

speech therapy, recognize that a significant part of the problem of difference rests with the fluent speaking world. The feeling is that the fluent speaking community must learn at least to tolerate stuttering (Examples 6, 7 & 8).

Example 1

Just kind of going through the motions trying to please my family was what I was trying to do. By doing that I had to not stutter. I just got very good at hiding it.

Example 2

Occasionally, very often still, if I don't know the people and this is the very first time that I've been speaking to them, I want to keep the problem hidden...I guess thinking that they will think lesser of me.

Example 3

In everyday life...people who know I stutter are pretty accepting and its no big deal, but there are people I hide it from, too. They don't know I stutter...Sometimes I just don't want people to know. I don't want people to know because I don't want people to think less of me. So I avoid words, or saying things, or talking to them on the phone, things like that.

Example 4

That secrecy...that feeling of being exposed and keeping up a pretense, and then they ask you your name a second time and you stutter on it. It's like the whole fabricated castle has come falling down.

Example 5

They were talking about how to measure sulfur in the air. They were talking all around it, and here I had just run a year's project on it, knew exactly what they were talking about, how to go about doing it. I sat there, I sat there, I sat there, and I didn't say anything....A portion of that can be attributed to the fact that I didn't want to identify myself as a stutterer.

Example 6

They need to work on...being able to put up with my speech. I am only going to be talking to them for a few nanoseconds, they can put up with it.

Example 7

I'm not a normal person so why do I have to impersonate one?...If you don't like the way that I do things, that's your problem. It isn't mine.

Example 8

I want the opportunity to explain who I am as a person who stutters, and as a person who talks in what ever way, be it stuttering or not. I want the opportunity to explain who I am, to show who I am, and not to be prejudged...It's the opportunity to speak, or to explain, or to produce, or to present before being judged....As the years go, I think that we people who stutter are going to become, more and more, advocates on our own behalf...I think we are going to be blaming ourselves less for being faulted, and blaming society more for not being tolerant enough. I think that will go hand in hand with greater advocacy...and more striving... against stigma, much in the same way that many groups and persons with disabilities have been doing in a movement called the disabilities rights movement.

Along with negotiating the difference between themselves and the fluent speaking world, some people who stutter speak of reconciling themselves to their stuttering. There is a recognition that no cure for stuttering exists and, therefore, people who stutter must go about the business of accepting and integrating their stuttering as a meaningful aspect of who they are. The point is to overcome a sense of self-alienation and shame (Examples 1 & 2). Some people attempt the healing of this self-alienation by seeking out speech therapy. Their goal is to achieve a kind of speech that is more acceptable to themselves and others (Example 3). Other people who stutter, including those who are or have engaged in speech therapy, recognize a need to "own" their stuttering (Example 4). One subject envisioned that by accepting and integrating his stuttering the

experienced blemish and the accompanying shame can be recast into something that enhances one's life (Example 5).

Example 1

I think part of it is realizing that stuttering is not something really apart from me but that somehow it really is a part of me. I can't really deny that without denying part of myself. It may be something that I don't entirely like, but it's still a part of me which I have to learn to deal with.

Example 2

I really think that we, as people who stutter, need to embrace it. I mean that's how you get through all this crap.

Example 3

I don't believe I'll ever be cured, but that's not important. The important thing is that I can be working on my speech and talking in a way that is more acceptable to me and, I think, to others also. So it's not a type of disability where there is no hope.

Example 4

My attitude has changed from early on. I really do feel that my attitude has gotten to where I accept it, and don't want to eliminate it...The attitude of thinking that it was a flaw and that I needed to fix it, you know, like something's broken and needs to be fixed, now I am a person who stutters, and that is something that is part of me and I want it to be a part of me...For me to be more in control of it I feel like I need to own it. This is mine, I own it, I accept it. That gives me a sense of power, an empowering kind of control...That's the most healing part of my life now. I feel really peaceful.

Example 5

I consider stuttering to be my cross to bear, and it's a tough cross, it's all the time. Yet somehow I believe intuitively that this cross can also be transformed into a gem. It can be transformed into something of rare significance. This transformation will take place when I integrate the stuttering into my life...That word, integration, can mean acceptance, choosing myself, accepting myself...I can see how I've considered stuttering as an unacceptable part of...myself, with all the issues of shame that are involved...However, if I can integrate it, it will just be such a blessing...All this pain and all this suffering and shame and everything that has gone into

it, countless years of all this muck can be transformed into something beautiful, something worthwhile...It will keep enriching my life, the fact that I have touched such, that I have experienced such suffering.

Negotiating Constraints. People who stutter must deal with the constraints on speaking and living imposed by their stuttering. Some subjects, as mentioned earlier, point to the realization that stuttering was incurable and become reconciled to its presence in their lives (Examples 1 & 2). The focus changes from seeking a cure to discovering ways to manage life with a stutter (Examples 3 & 4). Given stuttering as a limit, people who stutter are confronted with deciding the extent to which it will limit participation in life. On one hand, the plight imposed by stuttering may encourage an individual not to participate in life fully (Example 5). Yet the refusal to take part may create other problems in living (Example 6). On the other hand, the person who stutters can choose to participate regardless of her or his stuttering. As one subject said: "I think, basically, I've just forged ahead no matter how I speak." Part of this "forging ahead" comes from an attitude that: "I don't need to be fluent to be a good communicator", and the attitude that life is meant to be lived and there are good things to be had despite the constraints of stuttering (Example 7).

Example 1

I was just really sick of stuttering and thought if I had [speech] therapy I would be cured forever. So I had therapy in the 9th and 10th grade...I didn't stop stuttering...Then I thought, when I go to college I'll

go to see a good [speech] therapist, and then I'll stop stuttering. I had therapy in college and realized that I wouldn't stop stuttering.

Example 2

It's a basic underlying physical problem that is always there. I think I've gotten myself reconciled to that. I don't like it, but it's a fact of life though.

Example 3

It suddenly began to dawn on me that somewhere along the way I was going to have to, like everything else in life, negotiate it. I think that's a process that took me, to get to a final point it took me years, but to reach that point to where it was useful for me I think it took a matter of days. I said well, that's the way it is. It's the old saw that, well, this is your deck of cards, this is what you're dealt, you play them, and you don't go back for aces and kings. You play what you got. I think when I reached a point that I accepted that, or at least accepted it on a workable level, then at that point I figured I could get by with it then.

Example 4

There was a point where I knew this was...I'll use the word "incurable"...Coming to terms with it, I think, inevitably resulted from the fact I realized it's...incurability, and that it didn't matter if it was cured or not. There were other things to do to manage it effectively, and that's what it was all about...A direction and not a destination.

Example 5

It never leaves you, and the fact that it's inconstant means that you're often encouraged to avoid, postpone, delay, ignore. It leads you into all this labyrinth of escape.

Example 6

I would not take her places, not go on vacations, not order in restaurants, not answer the telephone...Instead of saying let's go to a restaurant and I'll do my best to order, I just wouldn't think of that. I felt like I caused a lot of problems in my marriage because I let stuttering interfere with my everyday life.

Example 7

Life has got to be lived...What it boils down to is that if you don't want to be a hermit then you've got to get out there and give it a try. It may be painful

at times, but if you don't do it then you just miss out on so much. It boils down to either having some pain or missing out on lots of good things. What it boils down to is that I like the good things more than I fear the pain.

Communities of People who Stutter. Another way that people who stutter deal with struggle, difference, and limits is to form their own communities of people who stutter such as local support groups and national advocacy groups. Being part of a community of people who stutter affords a sense of empowerment, belongingness, and possibility that may not be available in everyday life. The following examples describe the experience of attending an annual convention of the National Stuttering Project (NSP). The NSP is an national advocacy group for people who stutter (Examples 1, 2, 3, 4, & 5).

Example 1

Here [at the NSP convention] the vast majority are people who stutter. That becomes the normalcy, and there's a very tiny minority of people present, mostly spouses and some speech pathologists, who are fluent people, but they are a tiny minority so it just reverses the whole world. It feels like power to be in this majority in this community. That's one feeling. The second feeling, which probably to me is even more important is that it puts me at ease...I know that the person will be accepting of stuttering.

Example 2

It's a great feeling [attending an NSP convention]. It makes a big difference in your life, at least it has for mine. You feel that you belong. You feel that you're a part of the world. You feel that there is meaning to life...I'll go back home energized.

Example 3

It is a very special feeling because when you are here then you don't feel in the minority because you don't have to be worried about how you're sounding. Here your fluency or lack of fluency doesn't matter. It's like a

small family. There is a special bond which is formed with people from all over the country, and Canada, and even England and Germany which transcends race and religion. We all have a common bond, so I feel more relaxed here than any place in the world.

Example 4

People know, if I'm struggling, they know what to do and not do. They're not going to interrupt me and start talking for me, or they're not going to tease me or make fun of me....There is something about being amongst people of your own kind. It's like common ground...It's real peace oriented. It seems like everyone here is going to be themselves...I feel really connected to people in a close way, almost like family....They know what it's all like, the empathy...and real understanding. Not just simply being able to say yes I can relate to what you are saying, but actually having this gut understanding because it's actually happened to you.

Example 5

Here you're in an environment where everybody understands.

Example 6

I feel like I'm with family. I feel like I'm at home. I don't feel different. I feel accepted. It's like an oasis in the desert...I let my hair down, don't have to pretend, don't have to hide. I can just be with other people who are like me.

CHAPTER 4

DISCUSSION

The goal of this research was to provide a description of the experience of living with a stutter. The results revealed that stuttering is experienced as a burden that renders the person who stutters as negatively different, and as limiting the extent to which that person will be able to experience her or himself as participating in everyday life. Given this experiential meaning, people who stutter are confronted with coming to terms with and negotiating the impact of stuttering on their lives

Theme 1: The Burden of Stuttering

Theme 1 revealed that stuttering is experienced as a difficulty or hardship in situations requiring speaking with other people. One aspect of this burden is the experience of dis-coordinated speech. The descriptions of stuttering reported in the present study seem to resemble those reported elsewhere; Bloodstein (1987), for example, reports that disruptions in speech production are experienced by people who stutter as "the feeling of being physically halted in [the] attempt to speak. For a time they are literally unable, by ordinary definition of that word, to move or to control their speech organs for the purpose of

articulating the intended word" (p.23). These experiences tend to be accompanied by feelings of tension in muscles involved with articulation, phonation and respiration (Snidecor, 1955).

A second aspect of Theme 1 concerns interactional order. The present study found that people who stutter are sometimes confronted with unequal status positions, listener impatience, and loss of listener attention. One way of conceptualizing these findings is that stuttering is experienced as an unpleasant event by the listener. Rosenberg and Curtiss (1953) investigated the influence of stuttering on eye contact, hand movement, and other bodily movements of listeners. Results showed that stuttering acts as a behavioral depressant for the listener. "During stuttering, loss of eye contact by the listener is maintained for longer continuous intervals, and for longer duration" than for fluent speech. The frequency with which listeners initiated hand movements was found to decrease during stuttering. In addition:

other bodily movement is significantly depressed during stuttering both in duration and in the number of times a movement is initiated. The listener starts a "bodily movement" less frequently and for a shorter interval during stuttering. Finally, the total amount of conversation during stuttering is depressed. (p.359)

Rosenberg and Curtiss (1953) conclude by suggesting "the 'avoidant' activities of the listener may be of significance in classing stuttering as a negative reinforcer (noxious stimulus) to the listener" (p.361). Similarly, a study (Krause, 1982) that observed fluent speakers and people who stutter engaged in dialogue found that fluent speakers tend to increase their head-nodding behavior and engaged in "compulsive smiling" when conversing with individuals who stutter thus implying "a lack of spontaneous affective expression of happiness" and having the "function of covering up expression of negative affects" (p.108). In addition, listeners may complete sentences for the person who stutters, ask the person who stutters to write down their statements, or not pay attention in order to minimize interacting with the person who stutters.

A third aspect of Theme 1 is the issue of communication of spoken message. It was found that people who stutter may sometimes experience the listener as not comprehending the intended message. In a study of the influence of simulated stuttering on listener recall of information, Hult (1976) found that stuttering interferes with listener recall compared to fluent presentation of the same information. A second study (Cyprus, Hezel, Rossi, Adams, 1984), however, found that stuttering interferes with recall primarily when listeners attend to the stuttering rather than to the information presented. Listeners attended primarily to

stuttering rather than presented information when stuttering was severe. Apparently, it is listener attention to stuttering rather than stuttering itself that hinders communication of a message. In fact, Duffy, Hunt, and Giolas (1975) found that four types of disfluencies (broken words, part-word repetitions, prolongations, and interjections) did not interfere with listener recall of information.

Difference and Constraints: Themes 2 and 3

Theme 2 (Difference) revealed that stuttering renders a person who stutters as different from fluent speakers, and this difference may be perceived and experienced as negative. Indeed, people who stutter reported experiences of stigma, prejudice and alienation. It is commonly assumed, however, that people who stutter have distorted perceptions of their social relationships (Cooper and Cooper, 1985; Cooper and Rustin, 1985). McDonald and Frick (1954), for example, contend:

the stutrer will frequently project his own feelings about his stuttering in such a way that, if he is experiencing feelings of shame, embarrassment, self-pity, etc., he will tend to perceive these same feelings in his listener. He will be quick to

interpret the most innocent action or remark of his listener as being evidence for what are really his own feelings. (p.306)

In contrast, research on behavioral (Rosenberg & Curtiss, 1954; Krause, 1982) and attitudinal (e.g, Yairi and William, 1970) reactions of listeners to stuttering and people who stutter reveals that such reactions as generally negative or different from reactions to fluent speech and speakers, and participants in the present study appeared to be aware of those negative and different reactions. McDonald and Frick (1954) point out that "more often than not, nothing in the way of a negative reaction will be noticed by an objective observer" (p.306). While the usual tendency of the "objective observer" would be to discount the perspectives of people who stutter as invalid, the results of the present study suggest the opposite course. People who stutter have a vantage point from which they can contribute important perspectives about stuttering (Moore & Perkins, 1990) and living with a stutter (Quesal, 1989) that could not be provided otherwise.

Theme 3 (Constraints) revealed that people who stutter experience limits in relation to their speaking, educational and employment opportunities, and social relationships. In terms of speaking and education, teacher's attitudes toward their students have been found to influence students' performance in the classroom (Rosenthal, 1968), and

Williams, Melrose, and Woods (1969) suggest that low academic achievement by stuttering boys of normal intelligence may be partially attributed to teachers' negative expectations of boys who stutter. In addition, an early study by Johnson (1934) found that oral recitation, which was a routine task for fluent speakers, was "a source of keen humiliation, discouragement, and even scholastic failure" for many people who stutter. Similarly, Fruewald (1936) long ago found that college freshmen who stutter "rank definitely higher in intelligence than the general freshman college population" (p.51). These findings suggest that some academically qualified people who stutter either do not attend college or do not succeed in college. Given the early dates of these studies, research is needed that both determines the extent of their present validity, and addresses cultural, social, attitudinal, and institutional barriers that prohibit academically qualified people who stutter from achieving educational goals.

Theme 4: Negotiating Life

Issues of limits (Theme 3) such as social relationships as well as other concerns related to Themes 1 (Burden) and 2 (Difference) can be best addressed in conjunction with Theme 4 regarding the process of negotiating life. One part of this negotiating process is related to changing the attitudes of other people toward stuttering and toward

people who stutter. A second part is related to developing strategies and skills that facilitate coping rather than succumbing to the negative aspects of life with a stutter.

Changing attitudes toward people who stutter. Three general orientations have been established toward understanding the acquisition, maintenance, and change of stereotypes and negative attitudes toward the disabled: 1) the sociocultural approach; 2) the motivational approach; and 3) the cognitive approach. A thorough review of these approaches to the general topic of stereotypes can be found in Ashmore and Del Boca (1981).

The Sociocultural Perspective. The sociocultural approach argues that individuals acquire negative attitudes and stereotypes about people who stutter in terms of exposure to people who stutter, media portrayals of people who stutter, and other socializing processes, for example, stuttering is listed in the Diagnosics and Statistical Manual of Mental Disorders of the American Psychological Association (1987). "This perspective suggests that there will be widespread agreement among members of a culture with regard to which groups are stigmatized as well as to how those groups are stereotyped" (Crocker & Lutsky, 1986, p.101). The review of research in the introduction to this study suggests that negative stereotypes of people who stutter have been found to extend across many kinds of individuals including speech pathologists, teachers,

parents, and employers, and there stereotypes frequently refer to negative personality traits regardless of age and/or gender of the person who stutters. Yairi and Williams (1970), for example, found that boys who stutter are perceived as nervous, shy, withdrawn, tense, anxious, self-conscious, and insecure whereas Silverman (1982) found that a girl who stutters is stereotyped as boring, unsociable, bungling, uninfluential, pessimistic, and aimless.

The most simplest explanation for negative attitudes held toward people who stutter is that people who stutter actually possess the negative characteristics attributed to them. In other words, negative stereotypes accurately reflect the characteristics of those who stutter. This explanation misses the mark because empirical data show that people who stutter do not have any characteristics (other than stuttering) that differentiate them from nonstuttering individuals (Andrews, et al., 1983; Bloch & Goodstein, 1971; Bloodstein, 1987). In fact, Bloodstein's (1987) extensive review of research on personalities of people who stutter found:

The weight of accumulated evidence does not appear to indicate that the average stutterer is a distinctly neurotic or severely maladjusted individual in the usual meanings of these terms. The evidence that most stutterers perform well within the norms on adjustment

inventories is too strong to support such a view. Nor do their responses on projective tests seem to point to marked deviation from the normal or to coincide in any consistent way with the patterns of the classifiable neuroses as they are recognized on these tests...Second, there is little conclusive evidence of any specific character structure or broad set of basic personality traits that is typical of stutterers as a group. (p.208)

A second explanation, offered in detail by Woods and Williams, (1976) suggests that listeners respond to the situational states of people who stutter during stuttering and incorrectly infer negative personality traits. This explanation requires exposure to people who stutter for the attribution of negative characteristics. If exposure were necessary, however, then level of exposure and severity of stuttering should be expected to influence negative attitudes. Contradicting these expectations is Horsley and FitzGibbon's study (1987) showing that "individuals with different amounts of exposure to stutterers were generally equivalent in their stereotypic beliefs about stutterers" (p.31). In addition, a study by Turnbaugh, Guitar, and Hoffman (1979) revealed that negative stereotypes of people who stutter do not depend upon the severity of stuttering. In general, people who stutter were described as a homogenous group and negative personality traits were

assigned to all levels of stuttering severity. Differentiation among people who stutter was made only between individuals who had very mild and very severe stutters.

Although exposure to individuals who stutter is not necessary for a negative attitude according to sociocultural theory, some exposure to people who stutter may influence listeners' attitudes toward them. Listeners have been found to restrict their body movements when interacting with people who stutter (Rosenberg & Cutis, 1954; Krause, 1982), and the amount of eye contact between people who stutter and their listeners influences listeners' perceptions of individuals who stutter (Tatchell, van den Berg, & Lerman, 1983). Moreover, stuttering "can negatively influence the listener's evaluation of the style of delivery and the competence of the speaker" (Duffy, Hunt, & Giolas, 1975, p.112). These findings suggest that although exposure to actual people who stutter is not necessary for negative stereotypes, mere exposure to people who stutter may exacerbate or reinforce such attitudes toward them. Donaldson's (1981) review of research, however, shows that "structured experiences...with disabled persons consistently resulted in positive attitude change" (p.505). A common factor in successful structured exposure studies was that the disabled person be perceived as having at least equal status where status relationships were defined in terms of

age and/or social, vocational, and educational rank.

Research on changing attitudes toward the disabled in general seems to have important implications for changing attitudes toward people who stutter. First, speech pathologists and school teachers should have exposure not only to children who stutter but to adults of their age who stutter. Second, development of positive attitudes toward people who stutter might be facilitated through exposure to individuals of equal social, vocational, and educational rank who are successfully adjusted to their stuttering. However, further research specifically focused on structured exposure to people who stutter is clearly needed in this area.

An alternative explanation is that people who hold negative stereotypes are exposed only to limited and nonrepresentative samples of individuals to stutter. In the movie, My Cousin Vinnie, for example, stuttering is used in the film to underscore the ineptitude of an attorney (Zimmerman, 1992). An analysis of portrayals of stuttering and characters who stutter in Porky Pig cartoons found that "the type and sound of the stuttering cannot be called typical of that produced by 'real' stutterers since there just is too much variety in the imitated stuttering. It is not unreasonable to suspect that Porky's stuttering was produced for effect and not much was given to accuracy" (Johnson, 1987, p.235). Moreover, Porky Pig was typically

portrayed as harmless, timid, and accommodating. "Porky Pig's audience, especially those viewers who know little about stuttering, could certainly get a distorted view about the disorder of stuttering and of 'people' who stutter" (Johnson, 1987, p. 237)).

Results of studies reveal that positive attitudes and reduced discomfort toward the disabled can be facilitated through more balanced media portrayals (Donaldson, 1980; Sedlick and Penta, 1975). In particular, portrayals of disabled individuals who do not act in the stereotypic ways in question. Moreover, Shurka, Siller, and Dvonch (1982) studied the evaluations by nondisabled of disabled individuals portrayed as either coping with or succumbing to their disability and being responsible or not responsible for becoming disabled. They found that portrayal of disabled individuals as effectively coping with their disability and being not responsible for becoming disabled resulted in the most favorable evaluations.

The Motivational Perspective. The motivational approach argues that negative attitudes toward people who stutter are motivated by the psychological needs of listeners. From a psychodynamic point of view, the attribution of negative traits to other groups of individuals "is often ego-defensive in nature and represents the projection of thoughts or impulses that the attributor wishes to deny in himself" (Jones et al., 1984, 161). In

other words, listeners describe people who stutter as "nervous, emotional, anxious, insecure, and afraid" (Yairi and Williams, 1970) because the listeners themselves are threatened by, or made focally aware of, these characteristics in themselves when listening to a person who stutters. Projecting negative traits on the other allows listeners to direct their hostility and frustration toward the person and away from themselves. Barclay (1987) suggests, from a Lacanian perspective, that listeners are confronted with death anxiety when they encounter a person who stutters; that is, fluent speakers tend to perceive a disruption in the typicality of the speech situation when they encounter a person who stutters. Stuttering is experienced by the listener as interfering with the taken-for-granted ways of communicating. Listeners experience the situation and the person who stutters as abnormal. Wertz (1988) has shown that "as an element of being, abnormality has an index of unruliness, strangeness, uncanniness, antipathy, and senselessness vis a vis the home order, which it threatens with a sort of anti-form" (p.214).

Using as an example Melville's (1981) portrayal of Billy Budd as a person who stutters, Barclay (1987) asks: Might Billy represent that part of Melville's own character which must be killed in a self castrating act symbolic of the accession to the symbolic order...which all men must achieve? Melville writes Billy's hanging

scene as a crucifixion in an ironic effort which laments what he...knows is a necessity for each individual...Melville through his character, Vere, has no choice but to sentence Budd to hang. The necessity for each individual is to accede to the symbolic order. It is with this order that death, if not mastered, can be kept at bat - at a distance. (p.179)

An alternative and more plausible motivational explanation for the apparent need to "crucify" people who stutter can be found in Dembo, Leviton, and Wright (1975). They hypothesize that "normal" people want individuals perceived as "different" to suffer as an indication that the assets lacking in "different" people are valuable and important. Katz, Hass, and Baily (1988) found that people tend to respond more favorably to disabled individuals when the disabled are perceived as unhappy. These findings reflect Lerner's (1970) contention that people need to believe in stable relationships between what they do and what they receive as a consequence of their actions. This "just world" hypothesis suggests that people require a sense of control over their lives. One way this sense of control is gained is by assuming that others must be bad or have done something bad to warrant their perceived affliction.

Donaldson (1980) reports that the psychodynamic

analysis of prejudice as a method for altering attitudes toward the disabled has not been explored extensively. One study (Yerxa, 1971), however, using a structured self-instructional program that facilitated exploration of psychodynamic reasons for holding stereotypic attitudes resulted in more positive attitudes toward disabled persons. Dickson (1990) presents a brief psychodynamically oriented description of what it is like to be a fluent person listening to someone stutter:

The fundamental feeling is always the same: frustration...My frustration has as much to do about me as it does with someone else's feelings or someone else's speech...Experience has shown me that stuttering frustrates me most when I already feel frustrated...and don't know it, when I haven't consciously recognized my frustration. The stuttering is then a trigger that releases my unacknowledged frustration...I am frustrated at me, at some part of my life...The stuttering was just a lightning rod for my frustration, which sprang from other sources - sources within me...I project my frustration...As soon as I become conscious of it, the projection collapses and the stuttering no longer frustrates me. (pp.VIII-22 - VIII-23).

The Cognitive Perspective. The cognitive approach focusses on how negative attitudes and stereotypes arise as a result of the ways in which the listener processes and categorizes information. Current theories on social cognition and stereotypes suggest an interaction between attitudes the listener brings to a certain context and information made available in the context (Fiske and Taylor, 1984; Hamilton, 1981). This "schematic perspective" argues the importance of understanding how old information is employed in response to current situations as well as how beliefs are constructed in relation to new circumstances.

White and Collins (1984) hypothesize that listeners use their own experiences of speaking disfluently and the negative internal state that accompanies such disfluencies to make inferences about the personalities of people who stutter. To test this hypothesis, two groups of 40 subjects each used the Woods and Williams (1976) adjective check list to describe one of two hypothetical constructs: 1) a typical adult male who stutters, and 2) "a normally fluent male speaker who suddenly starts to stutter for a short period of time, after which he speaks fluently again". As predicted by their hypothesis, White and Collins (1984) found that the two constructs were positively correlated across each of 25 adjective scales, and that the adjectives chosen were mainly negative. This finding suggests that normally fluent

speakers use their experiences of states of temporary disfluency as a reference point for attributing traits in people who stutter.

The White and Collins (1984) study also suggests that no exposure to individuals who stutter is necessary for possession of negative attitudes toward people who stutter. Rather, negative attitudes derive from an inferential process in which the negative stereotype results from "the fact that the internal states associated with disfluent speech in normally fluent speakers happen to be negative" (White and Collins, 1984, p.570). Turnbaugh et al. (1979) and Woods (1978) argue that when fluent speakers are finally exposed to people who stutter, the fluent speakers negative attitudes toward their own disfluencies act as a self-fulfilling prophecy inducing people who stutter to behave in a way consistent with it. In other words, similar and repeated listener reactions of a certain kind (unusually negative) may condition the "self-expectations" and behaviors of people who stutter.

One way of facilitating more positive understanding of people who stutter may be through fluent speaker simulations of stuttering in everyday life situations. Clore and Jeffery (1972) tested the idea of disability simulations using experiences in wheelchairs. Nondisabled subjects either followed a designated route in a wheelchair or watched a role player from a short distance. Results

indicated that both disability simulation and vicarious observation positively influenced attitudes toward the disabled.

Donaldson (1980) suggests that disability simulations and vicarious observations should be done in situations that allow the participants to see the reactions of the nondisabled to the disability:

Movement through a largely unfamiliar group of people as a single role player may further enhance realism, allowing the role player to experience the possible frustrations of the condition but, perhaps more importantly, to experience reactions of nondisabled strangers. This observation of reactions or avoidance may partially account for the success of the vicarious experience in the Clore and Jeffery study, while suggesting a key factor in the success of a simulation experience. (p.509).

Simulated stuttering in everyday situations has been used during the training of speech-language pathologists (Hulit, 1989). Bodily and emotional reactions and reactions of others reported by participants appeared similar to those reported by people who stutter. Valuable insights about the experience of living with a stutter were gained by the participants. For example:

Several students wrote about the overwhelming sense of frustration one experiences before and during fluency

failure, but one student captured this thought particularly well:..." A simple question I've asked to so many people with no conscious effort now had become a task of enormous difficulty." (Hulit, 1989, p.212)

One important difference between simulated stuttering and living with a stutter mentioned by Hulit (1989) is that living with a stutter lasts a lifetime. "Students who submit themselves to the assignment of simulating stuttering...know that when they wake up the next day, they will be normal speakers" (p. 214).

Coping strategies for living with a stutter. Berry and Jones (1992) point out that attitudes toward people who are disabled tend to remain stable over time, and research on changing attitudes toward disabled individuals generally show mixed results. As such, a focus on effective coping strategies for people who stutter is needed. Part of these coping strategies are concerned with recognizing and dealing with ignorance and misunderstandings about people who stutter by fluent speaking individuals. Indeed, White and Collins (1984) suggest that negative attitudes toward people who stutter stem from judgment under uncertainty rather than from motivational influences. As Race (1972) points out:

It is incumbent upon all...disabled persons to be aware of the fact that almost all of those whom they encounter are also disabled -- handicapped by their unfamiliarity with persons who are physically different

from themselves, and unsure as to how to react. It is as important for the disabled person to accept the "incapacity" of the other, and to know how to deal with it, as it is for the non-disabled person to learn of the specific difficulties of the disabled. (p.222)

A domain of particular importance is employment.

Peters and Starkweather (1989) suggest "there seem to be few actual obstacles to the achievement of career goals when the stutterer is given the chance to be evaluated on his merits" (p.315-316). Studies by Hurst and Cooper (1983) and Silverman and Paynter (1990), however, reveal that people who stutter are evaluated based on their stuttering, and stuttering is not considered to be a merit by those who make evaluations. Silverman and Paynter (1990) point out that the person who stutters must be able to:

cope with the prejudice of potential employers, consumers of his or her services, and the 'general public'...A [person who stutters] who is a "fighter" and believes strongly that he or she can perform competently in an occupation is more likely to be successful in it than one who is not. (pp.89-90)

One study (Schloss, Espin, Smith, & Suffolk, 1987) has shown that training in assertiveness skills positively influenced the way that young adults who stutter performed in employment interviews. Assertiveness skills included: a) putting employers at ease, b) corrective feedback for

interrupting, c) responding to pejorative statements, and d) acknowledging positive employer behaviors. A second study (Collins & Blood, 1990) has shown that the tactic of acknowledging one's stuttering influences the attitudes of co-workers toward people who stutter. Specifically, significant numbers of female nonstutterers were found to prefer interacting with severe stutterers who acknowledged their stuttering rather than severe stutterers who did not. The study also found that people with mild and severe stutters who acknowledge their stuttering "receive more favorable ratings on intelligence, personality, and appearance than stutterers who do not acknowledge their stuttering" (p.79).

Further research on the tactic of acknowledging stuttering as a way to reduce listener discomfort has been studied by Silverman (1988). Forty-six college students used 81 semantic differential scales to evaluate one of two conditions: "a stutterer" or "a stutterer wearing a T-shirt on which is printed: 'I stutter. So what!'" Results showed "people who stutter wearing the T-shirt" were reacted to more favorably than they would otherwise. This study was systematically replicated (Silverman, Gazzolo, & Peterson, 1990) using store clerks and business people. The findings of the second study were similar to those of the first study.

Participants in the present study reported that membership in advocacy groups such as the National Stuttering Project facilitated their living with a stutter. This finding seems to contrast with Van Riper (1971) and French (1966) who suggest otherwise. Van Riper (1971) points out that while many groups and associations of people who stutter have been organized, few of them have survived for extended periods "perhaps because of the stigma that is felt when an overt identification is made exceeds the relief gained" (p.200). On the other hand, both French (1966) and Van Riper (1971) suggest that the intermittent nature of stuttering contributes to a tendency on the part of people who stutter to not associate with others who stutter:

Stutterers' groups are based on a deviancy that is intermittent, easily disguised, and socially penalized, and the associations tend to be unstable....The stutterer feels quite normal except when speaking -- and even then provided he is not stuttering...His fluent intervals make group identification with other stutterers difficult. (Van Riper, 1971, p.201)

While differences regarding attitudes about advocacy groups between the present study and earlier writings may be attributed to contrasting historical zeitgeists, further research is needed to clarify situational and dispositional factors that facilitate and inhibit participation in advocacy groups for people who stutter.

Finally, Merleau-Ponty (1962) points out that the stigmatized "have the choice between being an object of disapproval or disapproving of others" (p.435). For people who stutter, a part of this choice consists of refusing societal and cultural devaluations of stuttering and people who stutter, and fluency standards that prevent full participation in everyday life. As one participant in the present study expressed it:

Our disfluent speech makes us different and we will, with out a doubt, be treated differently. At one time, I considered myself handicapped only because that's what I was taught to believe. Speech clinics have labeled people who stutter as disordered...We are not disordered, we are different...I think the disordered are all those who have trouble accepting differences...Trying to make a person into someone he is not (stutterer into a non-stutterer) is not only impossible but, in my opinion, also disordered. Trying to change black people into white people in order to solve the problems of prejudice and discrimination is unethical and impossible...The same pertains to stuttering. So who are the disordered? The disordered are all the speech pathologists, speech scientists, or anyone who cannot accept a difference and covers this flaw by labeling a person who stutters as...disordered.

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APPENDICES

APPENDIX A

EXCERPT OF VERBATIM TRANSCRIPT
(I: Interviewer / P: Participant)

I: Please describe some situations or events that stand out for you as a person who stutters.

P: You're not going to like the first one that comes to mind. I think, frankly, I honestly believe that the most classic example is when I went up to a lunch counter and ordered a tuna fish sandwich and got two of them. This actually happened to me.

I: Really?

P: I ordered a tu-tuna fish sandwich and the person came over with two tuna fish sandwiches and I said I only or-ordered one whereupon he realized what happened and he said "Oh, I'll eat the other one. No problem, no problem". He was really quite convinced of the fact that he was sure of the fact that he just loved tuna fish sandwiches. That really is the most humorous story about stuttering. Were you trying to find humor?

I: I'm trying to find whatever you want to talk about.

P: So you're talking about just everyday occurrences?

I: Yes.

P: I had to go back behind the (college 1) cafeteria line to ask somebody something. I was asking somebody something and he began making fun of me so I think I told him if he didn't stop making fun of me I would wring his neck. Given the fact that this was a rather large man, it would seem really unlikely. I think he missed the whole thing. He missed the fact that I was angry. He missed the fact that what I was doing is called stuttering. I think he just missed the whole thing, and probably would still make fun of my stuttering should I ever have the misfortune to talk with him again.

I: What were you thinking and feeling?

P: I just remember being angry, really angry. I don't usually get that angry. I think I was just sort of in a foul mood. Most of the time I simply say I stutter, or I often talk like this, this is a bad day. Most of the time I'm much more matter of fact. I think it's unusual that I got as angry as I did. It was right from the gut, I remember that.

I suspect I was probably angry annoyed about something else and it just sort of carried over into that situation. That's what I suspect.

I'm not sure if anyone's talked to you about what it is like to be a woman who stutters, specifically.

I: Speak to me about it.

P: I'll share. I think that there is a stigma attached to being female in the sense that women are not taken as seriously as men by some people. At least this is what I believe to be true. There are people in the world who don't take what a woman has to say with the same weight that they might take what a man has to say.

I: Have you experienced yourself as not being taken seriously?

P: Sure. To be perfectly honest, the group of people that is most offending there is middle-aged white men....In terms of stuttering, it really becomes another area of "inadequacy" in the eyes of many people. Its another area in which I as a human being might fall short. So you have stuttering and the fact that I'm female.

I: So not only are you female, which in the eyes of many people makes you less legitimate, you also stutter which just adds to that sense.

P: I think it does. Actually, I think there have been a few studies on this, by the way, .Somebody wrote an article "Levels of aspiration among female Stutterers", I think that's the title, he touches on that, or she touches on that.

I: Talk about you level of aspiration.

P: I think, basically, I've just sort of forged ahead however I speak. I have been busy fighting a battle all my life that is only somewhat related to stuttering. I think it probably ties in with my stuttering at some level, but its not really the obvious battle that I've had to face, or that I've been fighting. To put it in a nutshell, I come from a family, my father's family, who reached really high levels of achievement in their fields. My father sort of brought this with him in his own family, and the amount of pressure that I felt in my life to achieve in my life has really been extraordinary. I'm five and a half years younger than my brother, and my brother basically took the awards. He was a high achiever. He took the awards and accolades and I was left wondering what to do. I think I was infantilized, sort of being patted on the back, you know,

"it's O.K. dear, you have something to offer too, sweetheart. It's O.K, you're a nice person. You're a sympathetic person". When in fact being nice and sympathetic wasn't anywhere near as important in my life as being smart. So it was sort of like winning the booby prize.

That's the battle that I've had to fight. I think the fact that I stutter has added to my sort of being second best, to being obviously flawed. Flawed first because I'm not this magnificent high achiever, what ever that means, flawed because I was younger and therefore to be taken care of and infantilized and patronized, but also flawed because I have this speech impediment. I was, therefore, less than perfect. I couldn't be pushed out ahead to make the family proud, you know, "go out dear and tell all those people about all those marvelous things you've done". I couldn't be pushed that way because I'd go out there and I'd begin stuttering. So I think there is a very insidious influence.

I think the battle I'm fighting is secondarily my stuttering, and it's because of my past. I think my primary battle is to be someone, to be somebody. A sort of battle on the side, sort of a connected battle, is to be someone despite the fact that I stutter. In terms of being flawed, I find that I overcompensate. I overcompensate for whatever I think I'm being pegged as. I expend a great deal of energy being out there, trying to be bright, trying to be intelligent, trying to be nice. I expend a lot more energy than many people feel that they have to. I think that's one reason why I'm always going. I'm making up for it. I'm making up for the fact that I've been perceived in a less, and had this tendency to see myself as being less than adequate. So I'm making up for it. I'm out there pushing. I just see myself going all the time. I don't stop and relax I don't just sit. It is really rare that I sit and relax. I'm always doing something that has to be done, that I think has to be done.

I: Can you relax?

P: Yes., I think I've learned more and more to relax. Relaxing involves giving myself a pat on the back and saying good job, good job, you've done well, sit and watch this stupid show on T.V. I think, now, as I see myself making more progress, it becomes easier to pat myself on the back, and easier to say good job, watch this silly T.V show, but it's been something I've really had to struggle with. I really had to struggle with not being wound up all the time. I guess I've been very much in pursuit of "normal".

I: Trying to be normal?

P: Yes, very much in pursuit, not of being normal in terms of character or personality because I think I've achieved

that, I think I pass as being pretty normal. I think I can do that. I spend a great deal of energy trying to be perceived or trying to perceive myself as living a normal way of life, you know, not wearing ratty jeans everyday, washing the dishes, getting up at a decent hour, going to bed at a decent hour, like I'm convinced there's a normal lifestyle that all these normal people live, and this seems to be my current fight. Once I get to school and I'm talking to a professor in the office, I'm pretty convinced that I'm normal and that I'm looked upon as normal. Its more the lifestyle I lead, and I'm constantly trying to achieve what is a normal lifestyle. That's how it seems to be playing out now.

I: When you were describing things that you are doing, or going through, you mentioned struggles and battles.

P: I think I did.

I: Do you experience yourself in a lot of struggles and battles?

P: Yes, I think basically along the lines of what we've been talking about.

I: (Person 3) suggested that I ask you about the "A Fish called Wand " protests.

P: Oh, right, alright, O.K. I should make the point that that was a struggle on behalf of people who stutter. That was less a struggle for me. There is such a thing as self advocacy and group advocacy. I was advocating less for myself and my own personal development and more for people who stutter. I mean it wasn't terribly hard for me to protest through picketing "A Fish Called Wanda. I did that because I felt that we had to take a stand. Our point of view on the movie had to be heard. I think the more immediate reason I did that is that...I picketed the movie because several people in our [NSP] group were really upset about that movie more so than I was personally upset.

I: What was upsetting about the movie?

P: I think the part that was most upsetting was one scene in which one character is trying to get the person who stutters to divulge a certain piece of important information crucial to the plot, and the person who stutters was blocking and couldn't give the information. I don't know if it was part of that scene or another that the character that was trying to get the information was eating fish, eating fish from the fish tank, and I suppose Wanda was one of the fish, trying to force the person who stutters to give the information. It

was like, if you don't tell me, I'm going to eat another fish. I think that was the scene, or the couple scenes, that upset people in my NSP chapter the most because the audience began laughing really, really, hard. We all assumed that they were laughing at the difficulty that the person who stutters was having in speaking. To hear a theater full of people laughing at a stereotype of a person who stutters as a stupid clown, I think that was what was difficult.

I: What was it like to be sitting in that audience and hearing those people laughing?

P: I remember sort of the urge to fall through the back of my chair. It was hard. It wasn't as hard as I would have thought because nobody knew I stuttered. I was passing because I wasn't talking. God forbid I should open my mouth. If it had been a character with cerebral palsy on the screen and I was cerebral palsied in the audience, was having difficulty keeping still, and therefore realizing that everyone knew I had cerebral palsy, I think it would have been a lot worse, but here I was passing for a nonstutterer. If I didn't say anything, no one would know. Frankly, I think I remember being upset for the other people in the group more than being upset for myself. I could feel everyone going, you know, really tensing up, and I think that was what I really felt. I felt concern for the other people in the group.

After the movie I happened to see another student from (college 1) there, and when I went over to her I was very, very much aware of the fact that here I was going to stutter. I might stutter after this movie with this character being mocked for stuttering. I remember being very self-conscious about it, more self-conscious about my stuttering than I might otherwise be. Like, here I am about to prove it all Here I am about to expose that I am like this fool in the movie. That was hard, that was hard.

The protest itself was actually empowering. It was easier in (city 1). It was easier there because the whole (city 1), (state 1) community is very avante-garde, leftist, not the whole community, but there are so many left wing people there who are in to this, that, or the other cause that they were really quite interested in what we had to say. The other cinema at which we protested was much less willing to hear our story, and we got mocked by some people.

I: What was that Like? Get into detail about both situations, about (city 1) and the other.

P: My reaction to the (city 1) situation was I was afraid that they might be taking pity. This sort of guilt trip, you know. Have you ever heard of the term "white middle class guilt for the poor?" I was afraid that they were perhaps

taking on fluent guilt. I was afraid that they were over reacting. I didn't want to be patronized. I didn't want people to embrace this cause the way they might embrace any other cause that might come down the pike. I wanted to state the case, I wanted them to be convinced on the merits of the case, not because it was another cause. I remember being nervous about that as though this is a little too much. This is sort of pushing reality here, let's get real, you know, what's the baggage that you folks are bringing to this? Fluent guilt? You know, don't patronize me, We'll state our case. either agree or disagree, but we'll do the work here. We'll do the work.

At the other cinema, that was harder in terms of being ignored and not being taken seriously. At the same time I was comforted to know that I had the sense that it was a slice of the real world. I wasn't being patronized, heaven knows. I was seeing how people really were taking this issue out there in the real world.

I: And how were they taking this issue?

P: Not terribly well. Basically, they thought that we were making too much of it, that everyone in the movie was being teased, and why don't we just lighten up. I think that was probably the basic reaction. There were a few people who just simply thought it was fun to tease people who stutter because we're obviously really messed up. But most people, I think the average opinion, on the part of the average person, whatever that is, is that we were just taking the whole thing too seriously, and we should just simply live and laugh. I was happy to see what the real world thought. It was miserable to be laughed at, but the overall feeling that I had from both of those incidents was that it was really empowering just to be there. The fact that we were there, doing the best we could, saying what we had to say, to me that was the most important thing. We got laughed at, we got told to move across the street by the cinema management, but at least we did something. I think that was the most important thing. I think everyone came back...I think most people came back from the (city 1) cinema happy, came back from the other cinema somewhat less than happy, everyone came through it empowered, feeling like we had control of our lives, or we were trying to take control.

I: What would you say to fluent speakers about the experience of being a person who stutters?

P: My initial gut reaction, which is probably the best one, is that I want the opportunity to explain who I am as a person who stutters, and as a person who talks in what ever way, be it stuttering or not. I want the opportunity to explain who I am, to show who I am, and not to be prejudged.

If you have a question, ask it. If you've never heard somebody talk like this, ask me why I talk like this. If you don't think woman or young people have anything to say, you know, wait till I've said it. It's the opportunity to speak, or to explain, or to produce, or present before being judged.

APPENDIX B

THEME CLUSTERS FROM INTERVIEW EXCERPT IN APPENDIX A

THE BURDEN OF STUTTERING (THEME 1)

Managing Interactional Order

Women are not taken as seriously as men by some people. At least this is what I believe to be true. There are people in the world who don't take what a woman has to say with the same weight that they might take what a man has to say...In terms of stuttering, it really becomes another area of "inadequacy" in the eyes of many people. Its another area in which I as a human being might fall short.

The protest [of the movie A Fish Called Wanda] ...was easier in [city1]...the other cinema which we protested was much willing to hear our story, and we got mocked by some people...My reaction to the [city 1] situation was I was certainly glad the people were interested in what we had to say. At the same time, I was afraid that they might be taking pity. This sort of guilt trip, you know?...Have you ever heard of "white middle class guilt for the poor?" I was afraid that they were over reacting. I didn't want to be patronized...What's the baggage that you folks are bringing to this, fluent guilt? You know, don't patronize me, we'll state our case, either agree or disagree, but we'll do the work...At the other cinema that was harder in terms of being ignored and not being taken seriously...I had the sense that it was a slice of the real world. I wasn't being patronized, heaven knows...Basically, they thought we were making too much of it...There were a few people there who thought it was fun to tease people who stutter because we are obviously really messed up...It was miserable being laughed at.

I expend a great deal of energy being out there, trying to be bright, trying to be intelligent, trying to be nice. I expend a lot more energy than many people feel that they have to.

Communicating a Message

I went up to a lunch counter and ordered a tuna fish sandwich and got two of them. This actually happened to me. ...I ordered a tu-tuna fish sandwich and the person came over with two tuna fish sandwiches and I said I only or-or-ordered one whereupon he realized what happened.

DIFFERENCE (THEME 2)

Stigma

The audience began to laugh really, really hard...They were laughing at the difficulty that the person who stutters was having in speaking. To hear a theater full of people laughing at...a stereotype of a person who stutters as a stupid clown, I think that was what was difficult.

After the movie [A fish Called Wanda] I happened to see another student from (college 1) there, and when I went over to here I was very, very much aware of the fact that here I was going to stutter. I might stutter after this movie with this character being mocked for stuttering. I remember being very self-conscious about it, more self-conscious about my stuttering than I might otherwise be. Like, here I am about to prove it all. Here I am about to expose that I am like this fool in the movie. That was hard.

The fact that I stutter has added to my sort of being second best, to being obviously flawed...I have this speech impediment. I was, therefore, less than perfect. I couldn't be pushed out ahead to make the family proud, you know, "go out dear and tell all those people about all those marvelous things you've done". I couldn't be pushed that way because I'd go out there and I'd begin stuttering.

Alienation

I was asking somebody something and he began making fun of me so I think I told him if he didn't stop making fun of me I would wring his neck. Given the fact that this was a rather large man, it would seem really unlikely. I think he missed the whole thing. He missed the fact that I was angry. He missed the fact that what I was doing is called stuttering. I think he just missed the whole thing, and probably would still make fun of my stuttering should I ever have the misfortune to talk with him again.

LIVING WITH DIFFERENCE

Social Relationships

I'm five and a half years younger than my brother, and my brother basically took the awards. He was a high achiever. He took the awards and accolades and I was left wondering what to do. I think I was infantilized, sort of being patted on the back, you know, "it's O.K. dear, you have something to offer too, sweetheart. It's O.K, you're a nice person. You're a sympathetic person". When in fact being nice and sympathetic wasn't anywhere near as important in my life as being smart.

NEGOTIATING LIFE (THEME 4)

Negotiating the Burden

[Protesting the movie A Fish Called Wanda] was a struggle on behalf of people who stutter...Our point of view on the movie had to be heard...It was really empowering just to be there. The fact that we were there, doing the best we could, saying what we had to say, to me that was the most important thing. We got laughed at, we got told to move across the street by the cinema management, but at least we did something. I think that was the most important thing. I think everyone came back...Everyone came through it empowered, feeling like we had control of our lives, or we were trying to take control.

Negotiating Difference

I've been very much in pursuit of "normal"...I spend a great deal of energy trying to be perceived or trying to perceive myself as living a normal way of life...like I'm convinced there's a normal lifestyle that all these normal people live.

I was passing [for a fluent speaker] because I wasn't talking. God forbid I should open my mouth...If I didn't say anything, no one would know.

I want the opportunity to explain who I am as a person who stutters, and as a person who talks in what ever way, be it stuttering or not. I want the opportunity to explain who I am, to show who I am, and not to be prejudged. If you have a question, ask it. If you've never heard somebody talk like this, ask me why I talk like this. If you don't think woman or young people have anything to say, you know, wait till I've said it. It's the opportunity to speak, or to explain, or to produce, or present before being judged.

Negotiating Constraints

Basically, I've just sort of forged ahead however I speak.

VITA

Peter James Columbus was born in Gardner, Massachusetts on October 20, 1957. He received a Bachelor of Science degree in Psychology from Fitchburg State College in 1982, a Master of Arts degree in Psychology from West Georgia College in 1986, and a Doctor of Philosophy degree in Psychology from the University of Tennessee in 1992.