

Speech Treatment and Support Group Experiences of People Who Participate in the National Stuttering Association



Manuscript to appear
in *Journal of Fluency
Disorders*

Research supported, in
part, by an NIH grant
(R01 03810) awarded to
the first author and the
University of Pittsburgh.

The National Stuttering Association Research Committee

J. Scott Yaruss

U. of Pittsburgh

Robert W. Quesal

Western Illinois U.

Lee Reeves

Chairman of the Board, NSA

Gerald Maguire

U. of California, Irvine

James A. McClure

NSA

Kenneth O. St. Louis

West Virginia U.

Lawrence F. Molt

Auburn U.

Anthony J. Caruso

Kent State U.

Fred Lewis

NIH, NSA

With additional help from:

Brett Kluetz, U. of Pittsburgh

Purpose

- To present a survey of National Stuttering Association (NSA) members' **experiences** in speech therapy and the support group
 - Have members participated in treatment, and if so, what was the nature of those experiences?
 - How many treatment experiences, how long did they last, what type of therapy was used...?
 - Do members participate in local NSA chapters?
 - How often do they attend meetings and what benefits do they experience from their participation?
 - What is the relationship between therapy and self-help?

Stuttering Support Groups

- Recently, there has been a dramatic increase in the prominence of self-help and support groups for people who stutter
 - More people participating in local chapter meetings and national conferences
 - Increased number of requests for information, both from people who stutter and from SLPs
 - Growing visibility through partnerships with professional groups like ASHA and IFA
 - Numerous presentations about support groups at conventions, and through ISAD

Support Groups & Speech Therapy

- After some early resistance, it now appears that a growing number of SLPs encourage their clients to participate in support groups
- There is even growth in the number of SLPs who participate in the groups themselves
 - The number of SLPs attending NSA conferences has grown dramatically in the past several years
 - The value of support groups has been affirmed through numerous discussions at the leadership conferences of ASHA's Special Interest Division 4

Support Groups & Speech Therapy

- Greater participation in support groups is seen by many to be a positive step, for support groups are believed to address aspects of recovery that may be lacking in some traditional treatment approaches
- Unfortunately, there is relatively little empirical evidence about the role support groups play in the recovery process for people who stutter

Empirical Evidence

- The few studies that have examined support groups have indicated that people who stutter experience generally positive results
 - Krauss-Lehrman & Reeves (1989): participants valued sharing “feelings, thoughts, experiences” and speaking in a “non-threatening place”
 - Ramig (1993): participation led to improvements in members’ feelings about themselves, their overall comfort in their personal lives, and their competence in their work environment.

Anecdotal Evidence

- There is ample anecdotal evidence that participants experience improvements in confidence, self-esteem, and even in fluency (though this is not always an explicit goal)
 - listserv discussions (STUTT-L and STUT-HLP)
 - popular press books on stuttering (Jezer, 1997)
 - personal stories of people who stutter (St. Louis, 2001)
 - The NSA's monthly newsletter (*Letting Go*) and publications such as *To Say What Is Ours*
 - The SFA's *Advice to Those Who Stutter*

The Need for Research

- Still, there is little direct evidence about the effects of support group participation, and even less information about the relationship between support group participation and traditional clinical treatment for stuttering.
- **Just as it is important to document the effects of therapy, so, too, is it important to document the effects of support groups**
 - Particularly true as more SLPs view support groups as part of the overall recovery process

The NSA Research Committee

- In an attempt to meet the growing need for empirical data about the effects of support group participation for people who stutter, the NSA has recently established a Research Committee (NSARC).
- The primary purpose of the NSARC is to function as a liaison between researchers and the NSA community to facilitate research on stuttering and support groups.

The NSA Research Committee

- The NSARC has also initiated a series of studies to evaluate the effects of support-group membership for people who stutter.
- These studies will examine aspects of recovery that are facilitated by support group participation and investigate ways support groups can be a useful adjunct to treatment
- This study is the first in a series of projects aimed at this increasingly important goal

The Present Study

- The purpose of this project was to collect basic information about the speech treatment and support group experiences of people who participate in the NSA.
- In addition to providing needed data about how people view their experiences, this study will provide the foundation for ongoing research about the effects of support group participation for people who stutter.

Method: Participants

- 71 adults who stutter who completed a questionnaire about their experiences in treatment and support groups
 - 175 total surveys were distributed to individuals who attended the 1999 Annual NSA Conference in Tacoma, WA (40% return rate)
 - Average age = 45 years (Range 15 to 76 years)
 - Reported age of onset of stuttering = 4.4 years (range 1 to 15 years)
 - 48 male (68.6%), 22 female (31.4%)

Method: Participants (cont.)

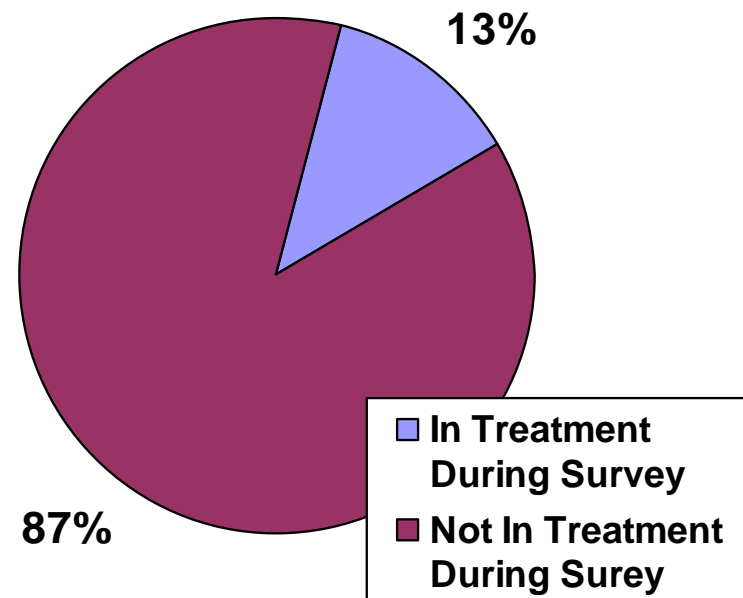
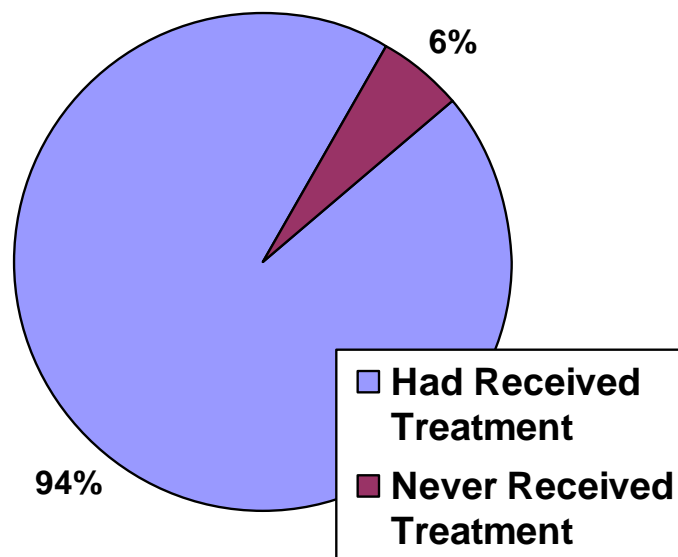
- This sample is obviously self-selected
 - Includes those individuals who took the time to respond to the survey (approx. 30 minutes)
 - It is drawn from a cross-section of the NSA membership who attended the conference.
- This represents an important subset of the NSA membership key to this research
 - The goal is to describe the experiences of people who participate in the group, so members who attend the conference are appropriate subjects

Method: The Survey

- The questionnaire contained nearly 50 items, with multiple responses for each item
 - Analyses involved calculation of the % of respondents who marked each option
 - Because many questions allowed respondents to indicate more than one answer, percentages often add up to more than 100%.
- Selected results are presented here, in two parts: “Speech Treatment Experiences” and “Support Group Experiences”

Results: Treatment Experiences

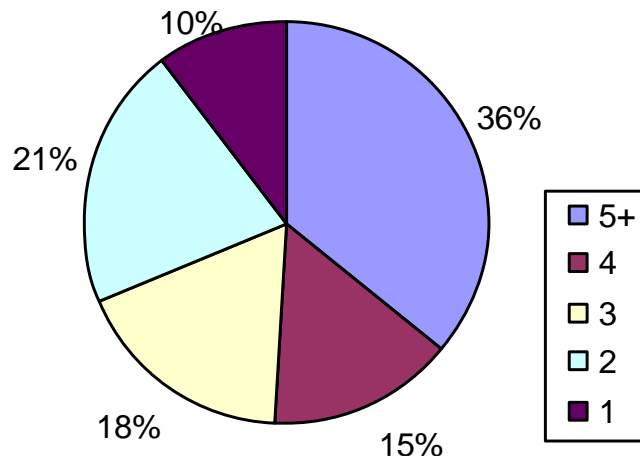
- The majority of respondents had received treatment at some point in their lives, though few were in treatment at the time they completed the survey



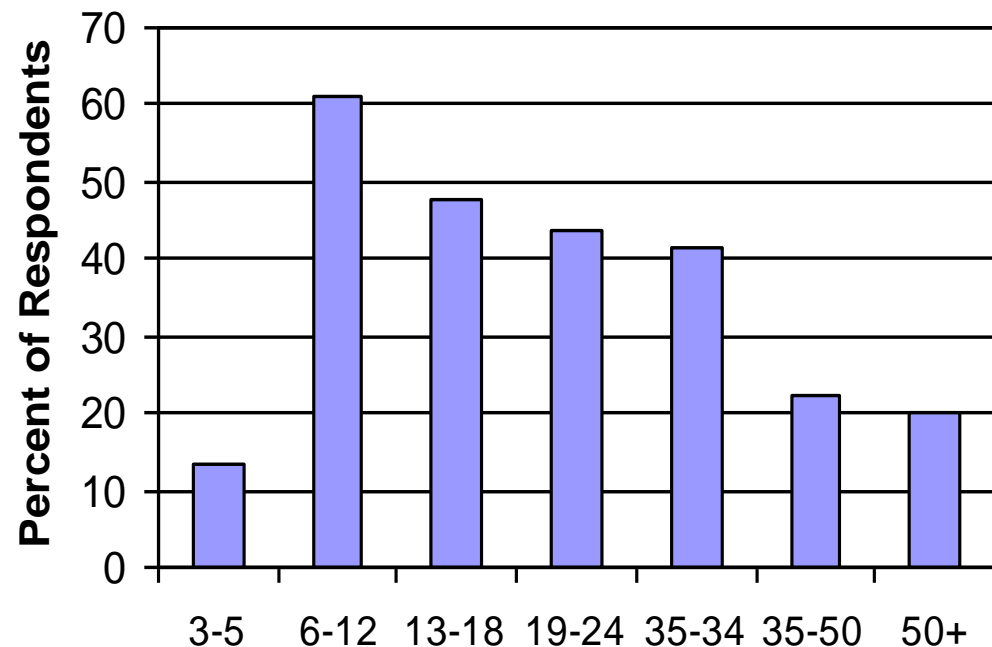
Multiple Treatment Experiences

- The majority of respondents had received treatment on more than one occasion, and at various times throughout their lives

Number of Treatment Experiences

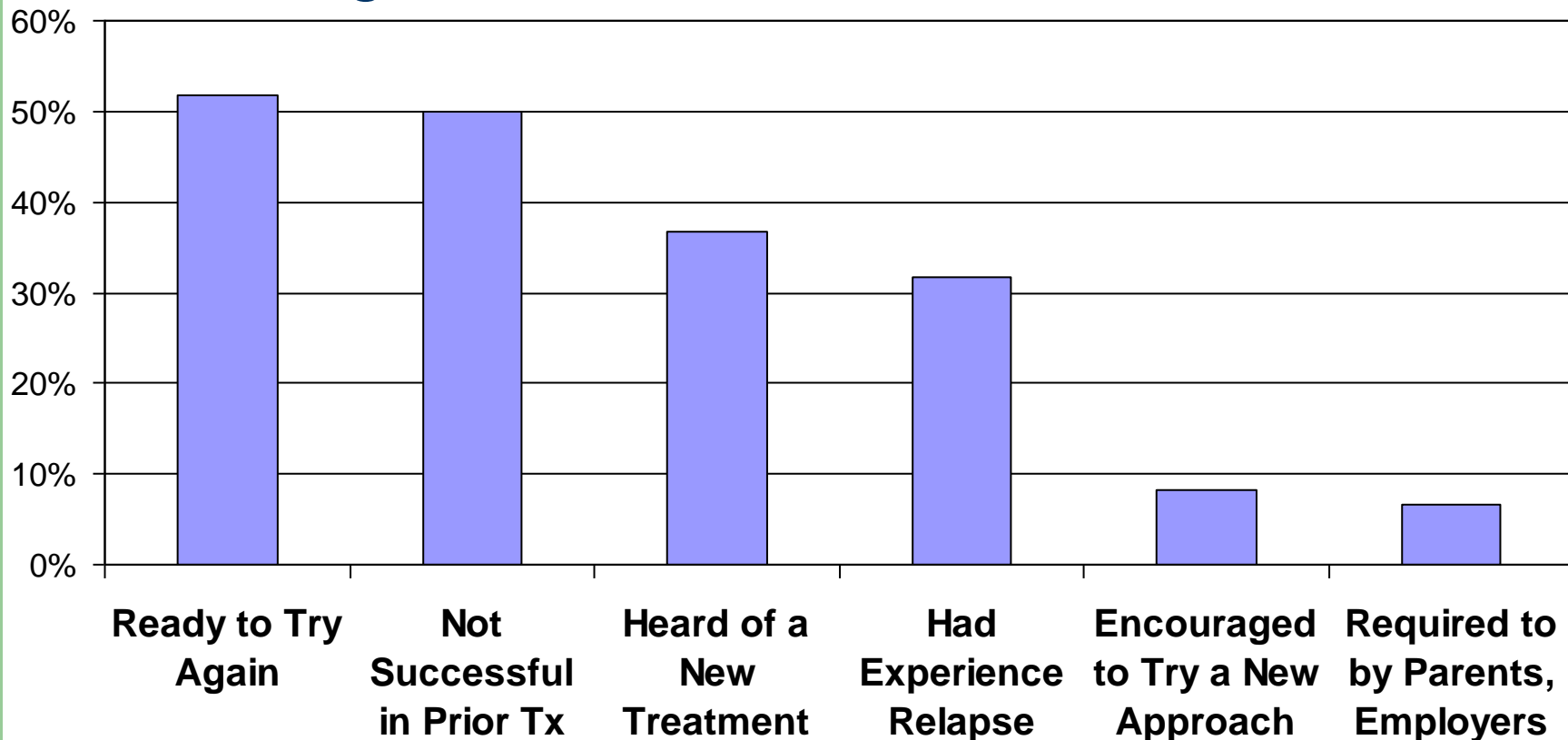


Age During Treatment Experiences



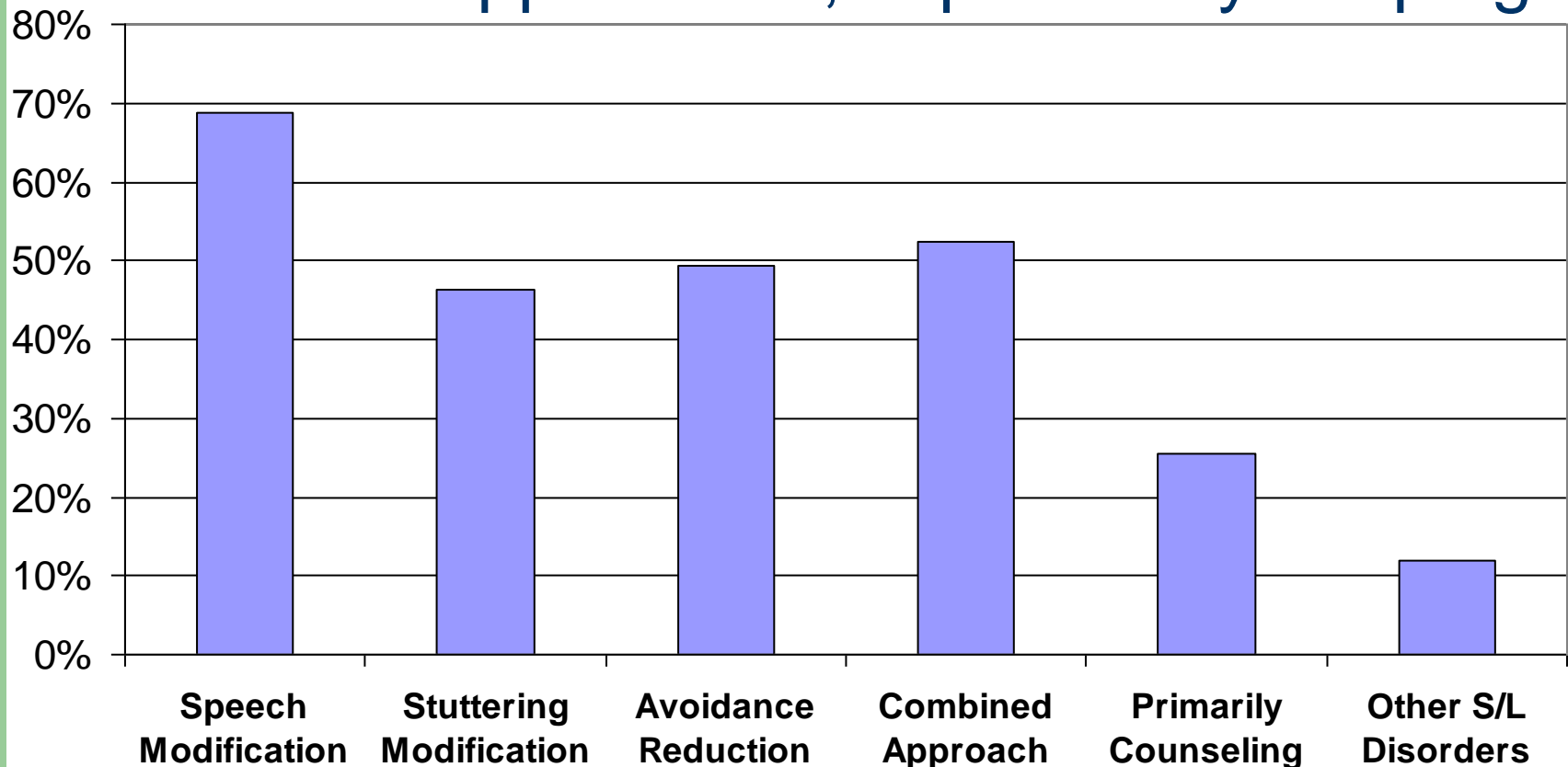
Reasons for Returning to Treatment

- Respondents indicated various reasons for returning to treatment



Types of Treatment Experiences

- Respondents had experienced a variety of treatment approaches, esp. fluency shaping

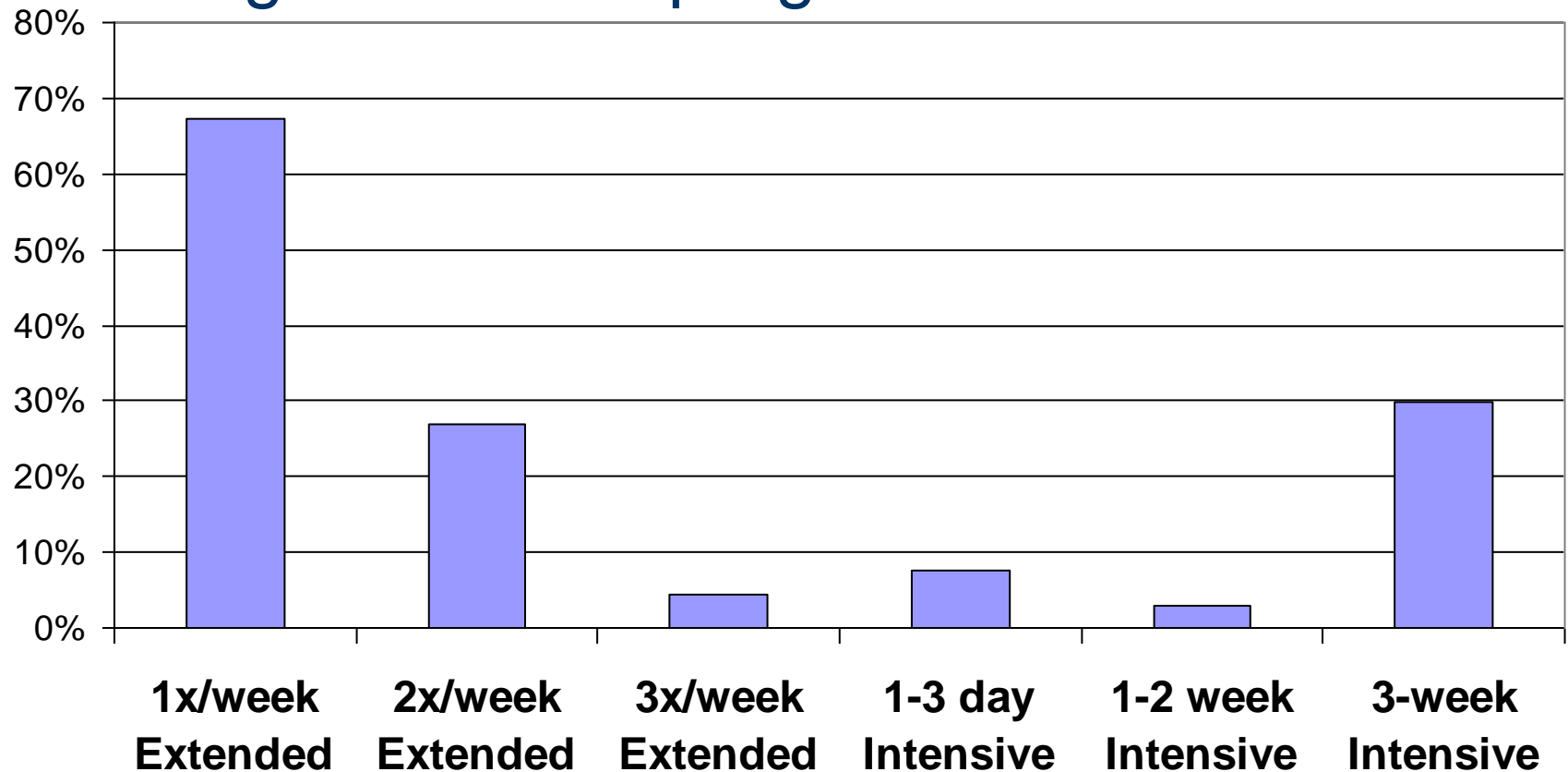


Outcomes & Treatment Approaches

- Respondents who reported that they had participated in fluency shaping therapy were also more likely to report that they had experienced a relapse or that their treatment was unsuccessful
- Similar co-occurrences were not found for respondents who reported participating in stuttering modification, avoidance reduction, or combined approaches

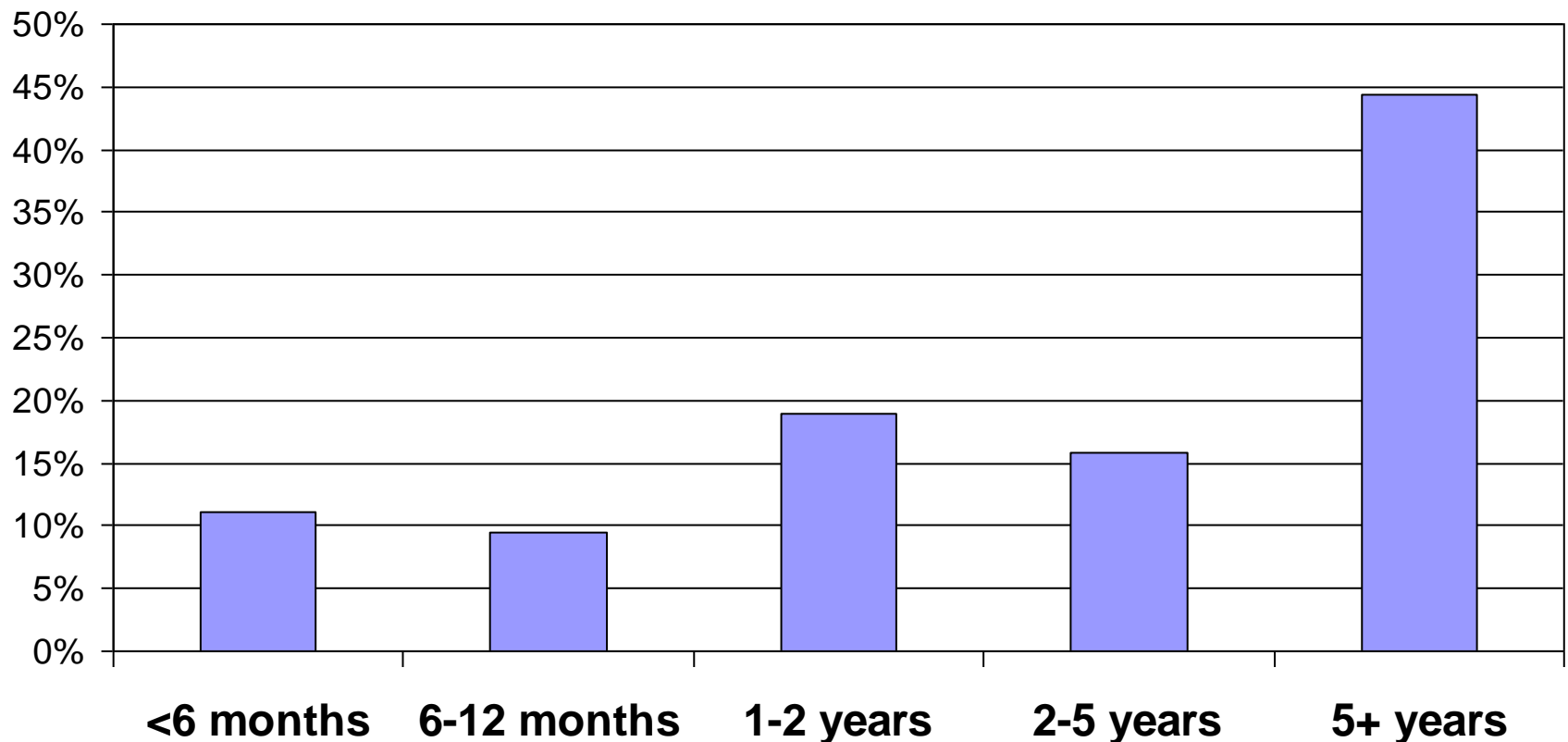
Duration of Treatment

- Treatment followed a variety of schedules, though extended programs most common



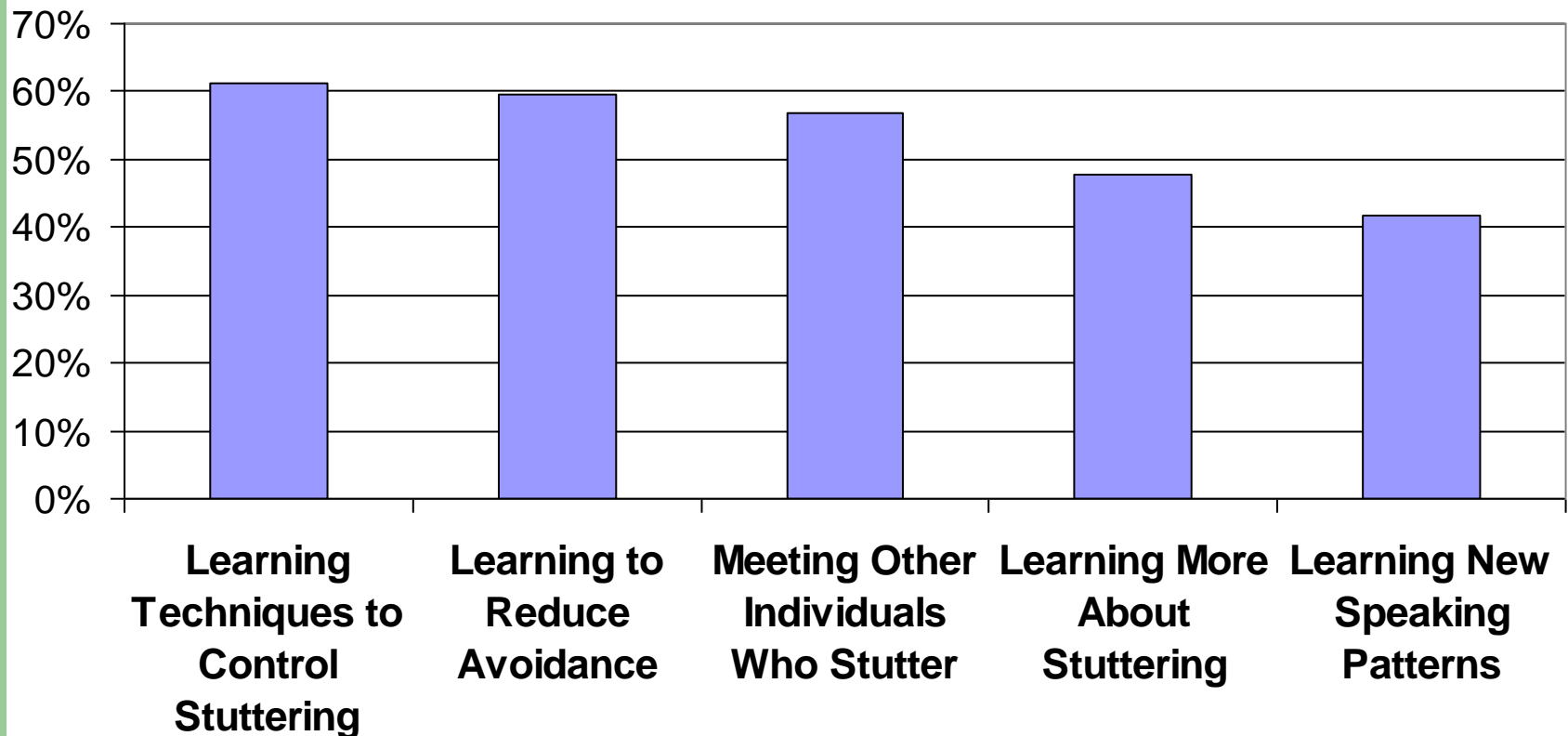
Total Time Spent in Treatment

- In total, respondents spent a considerable amount of time in treatment



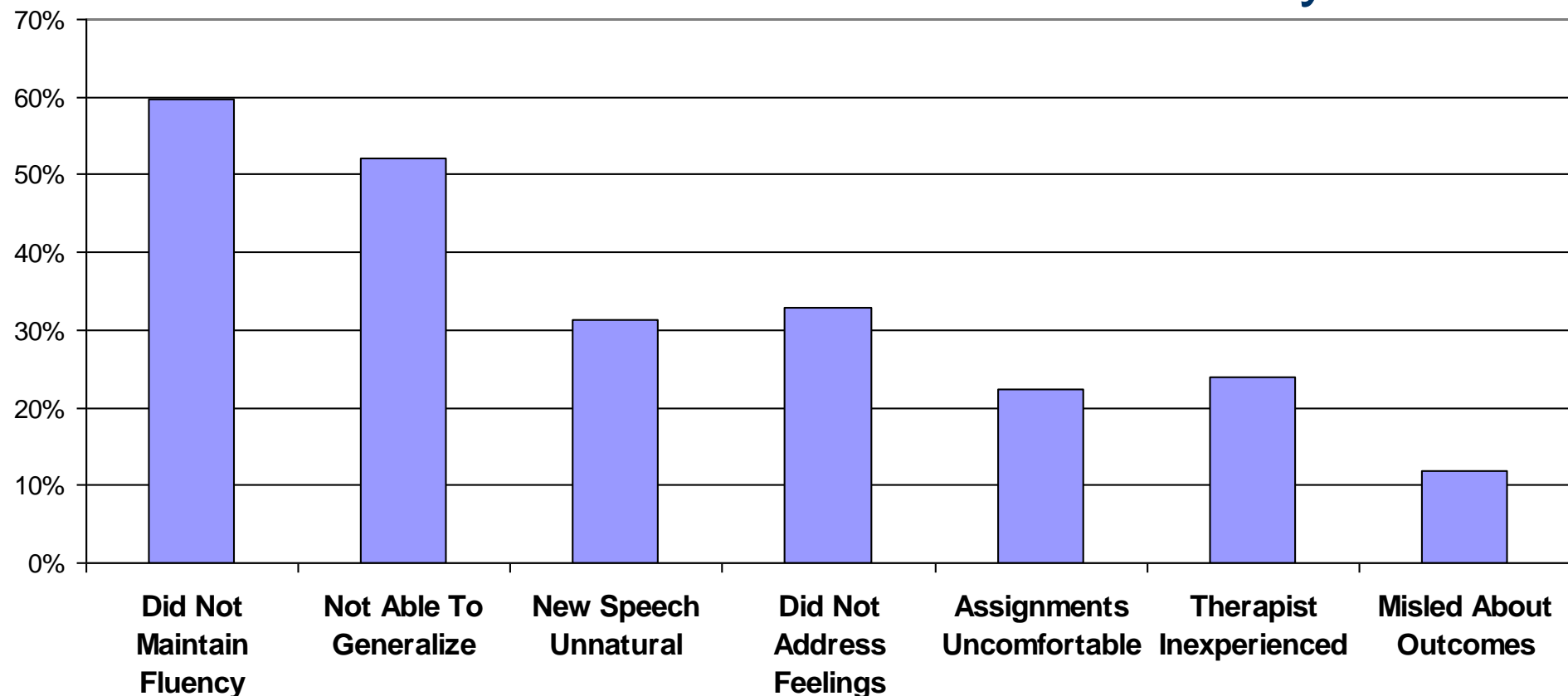
Satisfaction with Treatment

- Respondents identified several aspects of treatment to be satisfactory



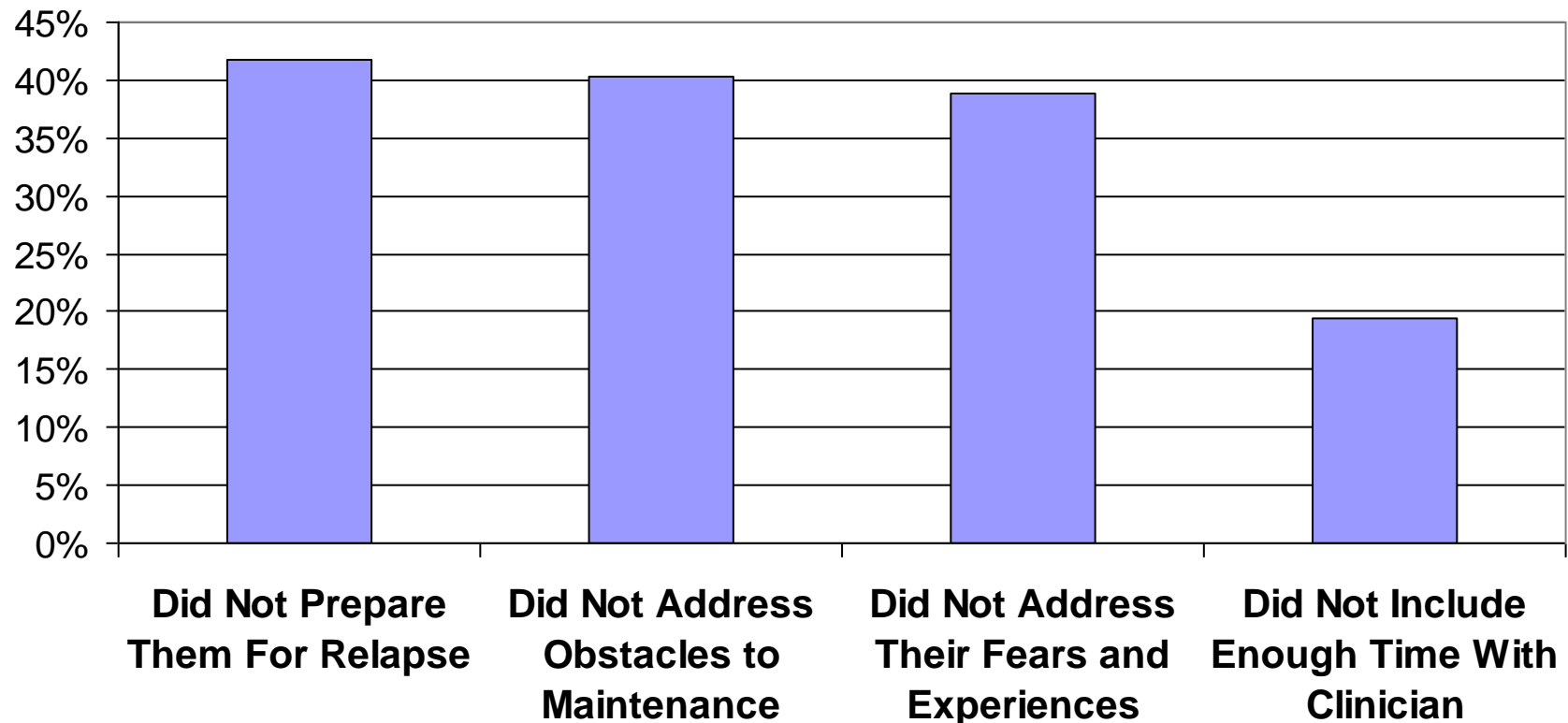
Dissatisfaction with Treatment

- Respondents also indicated several aspects of treatment that were not satisfactory



Factors Affecting Treatment Success

- Respondents identified several factors that hindered their success in treatment



Best & Worst Treatment Experiences

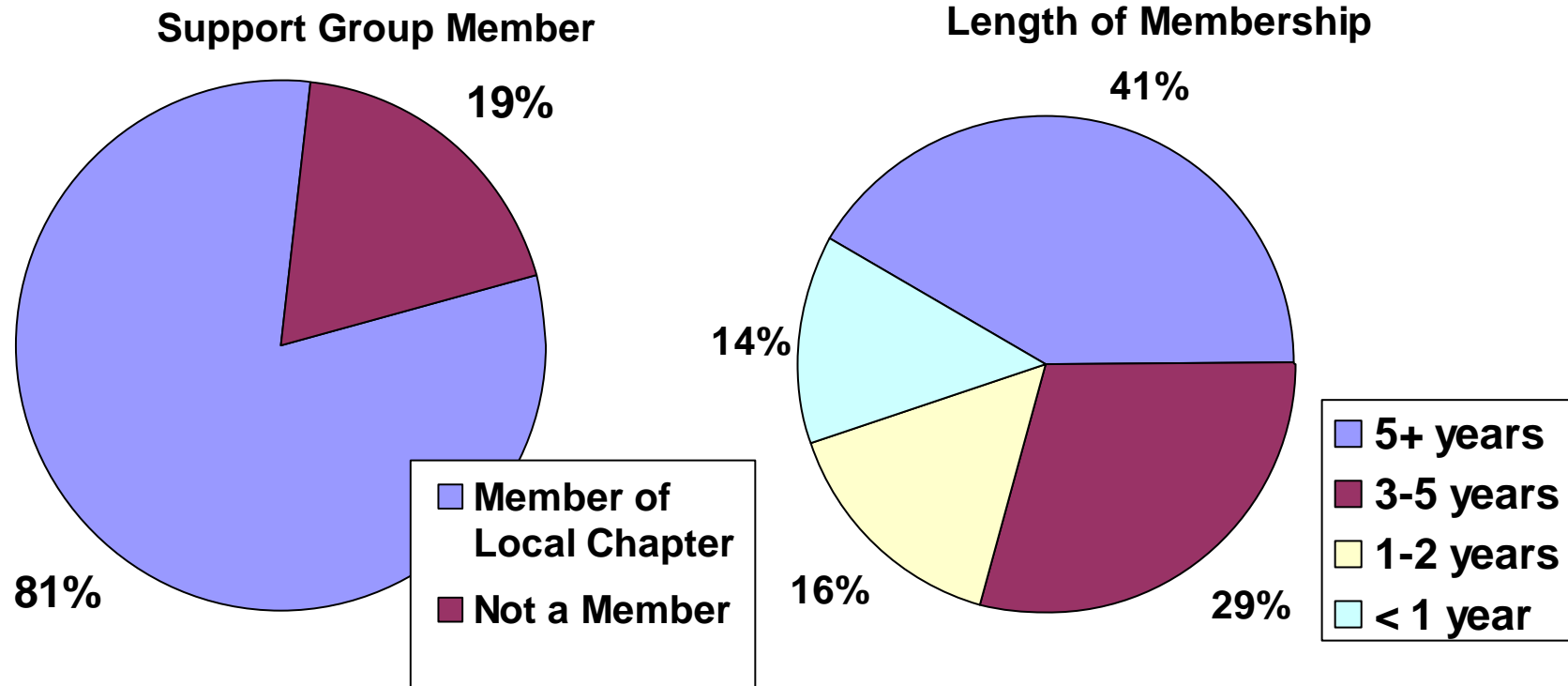
- Respondents rated their success more highly in their “best” treatment experiences, as compared to their “worst” experiences
- There was a significant correlation between respondents’ ratings of their clinicians’ skill and their success in treatment
 - This was particularly apparent for the respondents’ “worst” treatment experiences (i.e., for the “worst” treatments, respondents success was highly associated with the clinician’s skill)

Alternative Tx Approaches

- In addition to speech, respondents had experienced a variety of other treatments,
 - Psychiatry, altered feedback, masking devices, hypnosis, medication, metronomes, motivational courses, and vitamins/herbal remedies
- These treatments yielded varying success
 - Several reported moderate success with psychiatry and altered auditory feedback
 - Most reported little success with hypnosis, medication, pacing devices, vitamins, etc.

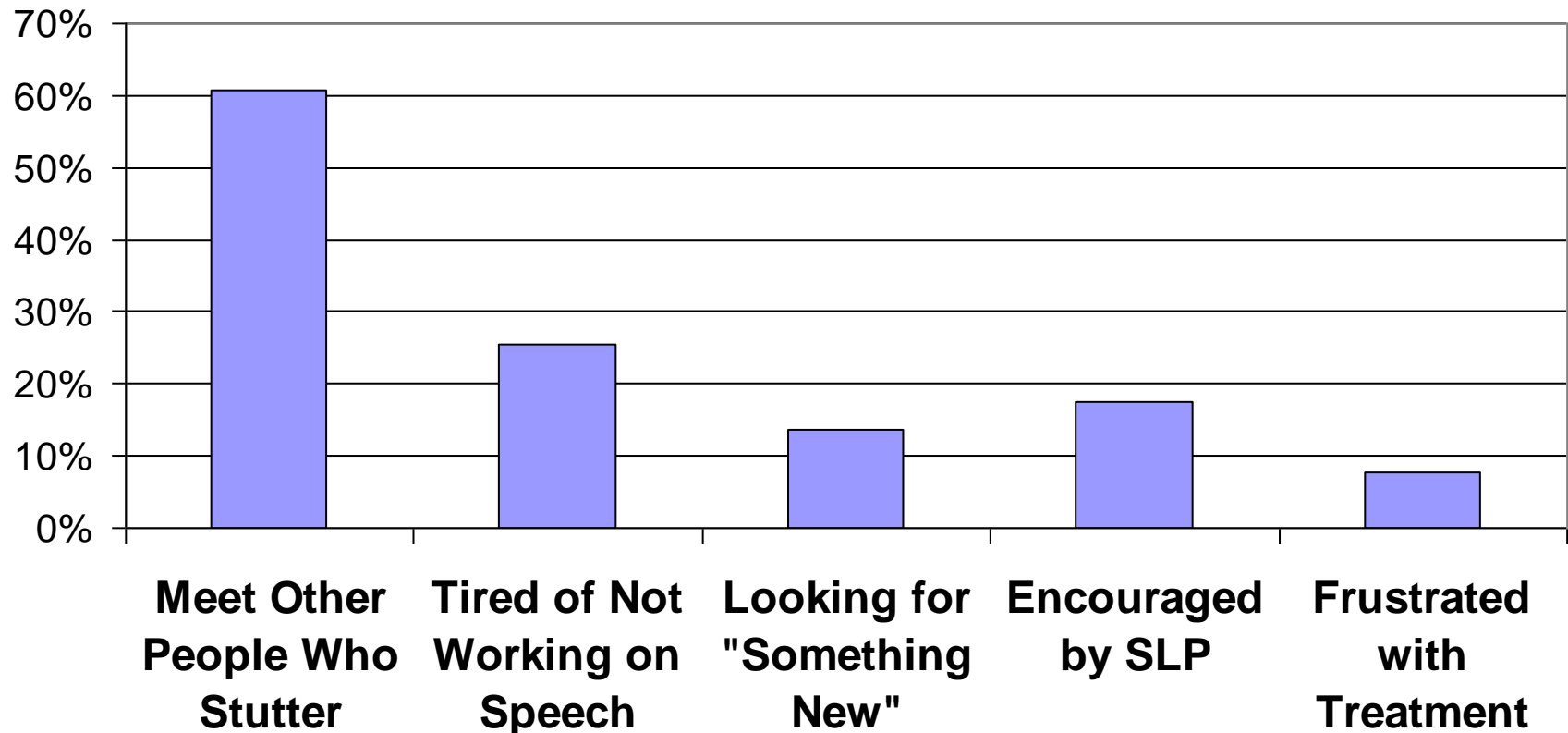
Results: Support Group Experiences

- The majority of respondents were members of local chapters, and had been for a while



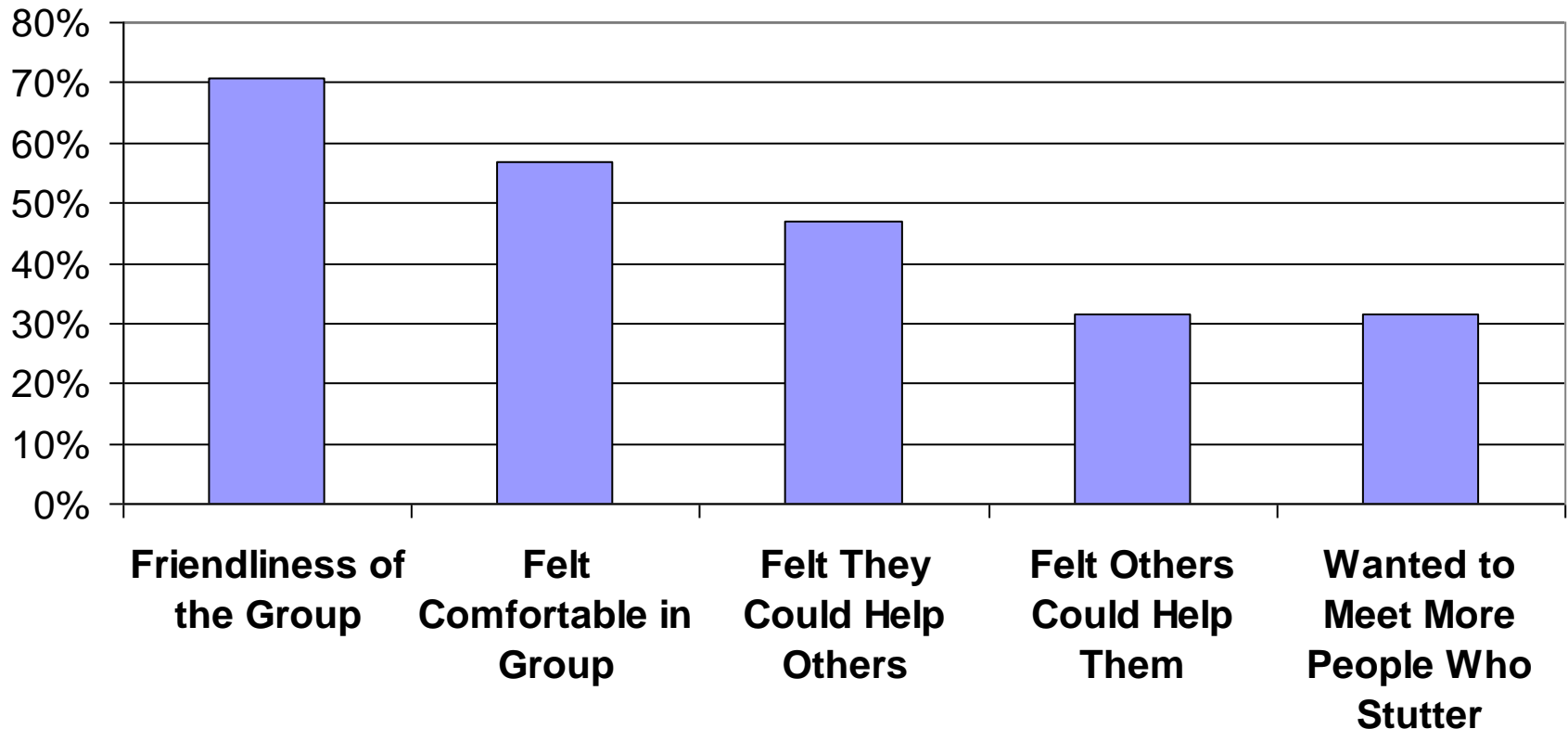
Attendance at Group Meetings

- Respondents indicated a variety of reasons for attending their first NSA chapter meeting



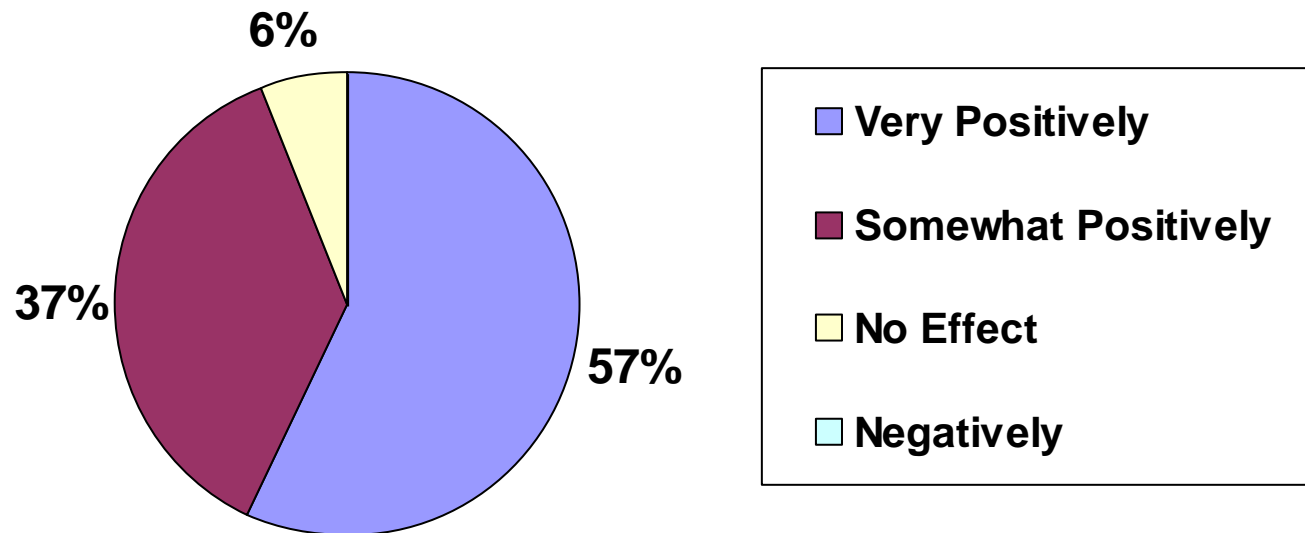
Attendance at Group Meetings

- Respondents indicated why they *returned* to the group after their first meeting



Support Groups and Self-Image

- Respondents indicated that participation in the support group had had a positive impact on their **self-image** and **acceptance** of themselves as people who stutter



Support Groups and SLPs

- Only 9 respondents indicated that they were encouraged to attend their first NSA meeting by an SLP
 - Nevertheless, 31.4% of respondents stated that they were in treatment at the time they attended their first meeting
- 12 stated that participation in the group *increased* their desire to pursue therapy; 5 stated that support group participation *decreased* their desire to pursue therapy

Support Groups and SLPs

- Overall, respondents indicated that SLPs were beneficial for people who stutter
 - Only 12.7% thought that SLPs do not provide adequate service, though 47.6% thought that most SLPs need more training
- Many respondents said that involvement with the group affected their opinion about SLPs
 - 68% said the effect had been positive
 - Only 3.5% said the effect had been negative

Support Groups and SLPs

- 51% of respondents indicated that the changes in their opinions about SLPs were mainly due to meeting SLPs at support group meetings
- The majority (80%) of respondents also indicated that SLPs should be involved in support groups meetings
 - Only 12.7% thought SLPs should *lead* support group meetings

Discussion: Treatment Experiences

- Consistent with prior reports, the majority of NSA members have received treatment, typically several times in their lives
 - Interestingly, very few recalled treatment in the preschool years, perhaps reflecting the fact that there was less emphasis on early intervention (or, perhaps, reflecting the fact that these adult respondents did not recall preschool treatment)
 - *Could it be that people who did not receive treatment in preschool were more likely to continue stuttering into adulthood?*

Different Types of Treatment

- Respondents indicated a variety of treatment approaches with varying degrees of success
 - Some preferred fluency shaping approaches; others preferred avoidance reduction, highlighting the fact that different people have different needs for treatment
- Interestingly, relapse appeared to be more likely for individuals who had speech modification / fluency shaping therapy
 - Although this does not reflect on the efficacy of these approaches, it raises important questions

Satisfaction with Treatment

- Respondents' ratings of satisfaction with treatment correlated strongly with their perceptions of clinician competence
 - This is particularly relevant given findings that many SLPs are not comfortable with their skills for helping people who stutter
 - As training requirements for stuttering are decreased, what effect will this have on respondents satisfaction with treatment?

Discussion: Support Experiences

- Most respondents were long-term members of the NSA support group, and nearly all attended local chapter meetings if available
- Participation in the NSA had a positive effect on self-image and acceptance of stuttering
- Interestingly, the aspects of therapy that were judged to be most beneficial were the same as those found in the support group
 - Meeting others who stutter, talking about talking, Learning to cope with stuttering more directly

Future Directions

- This study represents the first step in a series of studies designed to examine the potential benefits of support group participation for people who stutter
- Future studies will examine other aspects of support group participation, such as whether members achieve different levels of success in treatment compared to those who do not participate in support groups

FOR MORE INFORMATION...

- Send an email to

jsyaruss@csd.pitt.edu

- Or...give us your email address and we will send you a PDF version of this poster.

ALSO...

- Don't forget to visit the NSA booth to see the new materials, including our new guide for parents:

