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Support Groups for People Who Stutter: The Role and Perspective of Speech-Language Pathologists

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Support Groups for People Who Stutter: The Role and Perspective of

Speech-Language Pathologists

by

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Dedication

This thesis is dedicated to my wonderful parents for their support and encouragement.

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Abstract

Support Groups for People Who Stutter: The Role and Perspective of Speech-Language Pathologists

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In an effort to improve understanding of the role that support groups such as the National Stuttering Association (NSA) play in helping people who stutter, speech-language pathologists who participate in the NSA were asked to participate in a research survey.

Previous research and anecdotal evidence has shown that support groups not only benefit people who stutter, but also the professionals who work with them. Participation in the NSA can enhance SLPs' understanding of stuttering, and their comfort level and competence working with people who stutter. However, the relationship between support groups and professionals has not been adequately studied.

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BACKGROUND

Recent research demonstrates the clinical value of support group participation in the evidence based practice for persons who stutter those affected by stuttering to enhance outcomes of traditional speech therapy (Yaruss et al., 2002; Yaruss et al., 2007; Trichon, 2010, Tetnowski & McClure, 2010). To date, research related to the benefit(s) of support group participation has focused exclusively on the person who stutters (Krauss-Lehrman & Reeves, 1989; Yaruss et al., 2002). The value of support organizations is not limited to persons who stutter as participation can also significantly benefit speech-language pathologists (SLPs) who provide treatment for this unique clinical population (Reeves, 2006). Additionally, although referring clients who stutter to support groups has been recommended by top researchers in our field, the perspective of the SLP regarding client as well as self-participation has yet to be explored despite the call for such research nearly two decades ago (Ramig, 1993). Anecdotal evidence exists regarding the potential benefit of the support group participation for SLPs, but little is documented about the actual practices and attitudes of clinicians who participate in stuttering support groups (Gregory, 1997; Reardon & Reeves, 2002; Reeves, 2006; Yaruss, Quesal, & Reeves, 2007; Yaruss, Quesal & Murphy, 2002). In an NSA survey, McClure, D'Amico and Tetnowski (2009) gathered general opinions of adults and teens who stutter, parents of children who stutter, and included SLPs who are NSA members. However, the researchers did not ask SLPs about their participation in stuttering support groups nor about the perceived benefits they derive from that participation.

History of the movement

The original concept of self-help as an alternative to traditional medical intervention was formalized in 1935 with the creation of Alcoholics Anonymous (AA) in the United States. Their "12-step program" was a support framework for alcoholics who had not been "cured" by professionals, but who found camaraderie and spiritual redemption on their path to recovery. Since then, self-help groups have proliferated around the world and helped individuals cope with a variety of physical and mental health issues (Katz & Bender, 1990).

The World Health Organization (WHO), adopting the definition put forth by Katz and Bender, 1976, defines self-help or mutual aid groups as "voluntary, small group structures… usually formed by peers who have come together for mutual assistance in satisfying a common handicap or life-disrupting problem, and bringing about desired social and/or personal change…" In the United States alone it is estimated that more than 60 million people have participated in a self-help group (Reissman, 2000; Reeves, 2006).

Self-help groups gained legitimacy among both professionals and the public in the 1980s and 1990s (Borkman, 1999). Relative to stuttering, the consumer affairs director of the American Speech-language Hearing Association (ASHA), wrote an editorial in an ASHA publication (Diggs, 1990) urging professionals to recognize the growth of self-help groups established for disorders in their field, and wrote: "Consumers are becoming more interested in taking control of their own lives. Professionals need to recognize this trend and acknowledge the potential benefits of self-help." The benefit to individuals who stutter from their participation in self-help groups is seen in a variety of ways such as improving their self-image (Yaruss et al., 2002), helping them feel better about themselves and improving their confidence (Ramig, 1993), "sharing feelings, thoughts,

and experiences" and "speaking in a non-threatening place" (Krauss-Lehrman & Reeves, 1989).

The first formal self-help groups for those who stutter emerged in the United States and abroad in the 1960s (Reeves, 2006; Van Riper, 1973), and as an alternative for those who often had not been helped by traditional speech therapy (Gregory, 1997). The spirit of self-determination within the movement was embodied in the words of Michael Heffron, who described his intent in founding the first nationally recognized self-help group for those who stutter, The Council of Adult Stutterers, which met at Catholic University in Washington D.C. in 1965: "(I) would seek to make stutterers proud, not that they stutter, for only a fool would take pride in an affliction, but that they are doing something to help themselves" (in Van Riper, 1973, p. 169). Meetings provided a place where PWS expressed their feelings of frustration, shame, helplessness, and isolation with one another. In realizing they were not alone in their experiences, PWS felt liberated and translated their negative feelings into a group identity, self-esteem and empowerment (Bradberry 1997; Bloodstein, 1993). The opportunity provided within these meetings for PWS to openly discuss the impact of the disorder on their lives was a "revolutionary concept" for those affected by stuttering (Reeves, 2006).

Self-help activities around the world grew dramatically in the 1970s. In 1977, loosely connected self-help groups for stuttering around the country formed two national organizations: The National Stuttering Project (now known as the National Stuttering Association), and Speak Easy International. The groups became more organized, added advocacy to their missions, and established less reliance on professionals (Yaruss et al., 2007).

Recently the partnership between self-help groups and SLPs has grown. The cooperative relationship is evidenced by the presence of SLPs on the boards of the NSA

and ASHA (Yaruss et al., 2007). The alliance has been further strengthened by the establishment of the International Fluency Association (IFA) (Reeves, 2006).

Another major area in which self-help groups and professionals collaborate is in research and research recruitment for persons who stutter who have been historically difficult to locate in large numbers. Persons who stutter within self-help groups are often eager to participate in research (Bradberry, 1997), and NSA members have supported government-backed research which led to findings about genes for stuttering, and a number of other studies enhancing the field's understanding of the disorder. Facilitation of contact between self-help members and researchers was made easier in 2000, when the National Stuttering Association Research Committee (NSARC) was formed. In 2001, the NSA hosted its first joint research symposium between researchers and consumers, in which leading researchers and clinicians presented their findings to hundreds of self-help attendees.

Present day support group resources for those who stutter

Today, the National Stuttering Association (NSA) is the largest support organization of its kind in the world for persons who stutter (other notable organizations include FRIENDS – the National Association of Young People Who Stutter, Speak Easy International, The Canadian Stuttering Association, The British Stuttering Association, and the International Stuttering Association, an umbrella organization of self-help groups in more than 40 countries).

An almost all-volunteer nonprofit organization with a national office in New York City, the NSA operates chapters for adults who stutter in more than 110 cities around the country. As part of its Family Programs initiative, established in 2000, the NSA also has a growing number of TWST (Teens Who Stutter) chapters, and NSA Kids chapters, for

children ages 5 to 12 and their families. The NSA also holds regional workshops throughout the year, which provide self-help opportunities for children and adults who stutter, and Continuing Education Unit (CEU) training opportunities for SLPs. More than 740 attended the most recent NSA Annual Conference, a four-day event which includes workshops, keynote speeches, and socializing opportunities for PWS, their families and professionals.

The NSA also reaches the stuttering community through its Website (http://westutter.org), and published material, most notably its quarterly newsletters, *Letting Go* and *Family Voices*, available in print and online, children's books, and DVDs. The NSA also produces brochures to educate consumers and professionals and the public on topics such as early intervention, insurance coverage, and common myths about stuttering.

Examining the role of SLPs in support groups

The appropriate role of professionals within support organizations remains a critical issue for those who participate in and have studied the phenomenon of self-help (Borkman, 1999; Katz, 1993; Katz & Bender, 1990; Reeves, 2006). Presently there are no empirical studies examining the role of SLPs in stuttering support groups. From their empirical data, Krauss-Lehrman and Reeves (1987) reported that a support group for PWS would ideally welcome others including SLPs and graduate students, but only those who stutter should fill the leadership roles. Irwin (2007) suggested that SLPs take on the guide/coach/mentor role. Reeves (2006) believes that it is less important to label and restrict the roles of the members than it is for PWS and SLPs to work together to achieve the goals of their individual group. The author warns that professionals should be careful not to turn a meeting into a group therapy session (Reeves, 2006).

Benefits SLPs derive from participation in support groups

Although there is little evidence of the benefits SLPs derive from support group participation, there is anecdotal evidence from several sources (Gregory, 1997; Reardon & Reeves, 2002; Reeves, 2006; Yaruss et al., 2007). In recent years, self-help groups have presented continuing education workshops (Yaruss et al. 2007) and created published material (e.g. Stutterbuddies newsletter) that can be used in therapy to address affective and cognitive issues (Reardon-Reeves, 2002). In an NSA survey, SLPs reported that they find information provided by the Stuttering Foundation and the NSA helpful for themselves and their clients (McClure, D'Amico, & Tetnowski, 2009).

Reardon and Reeves (2002) suggested that school-based SLPs could use support groups as a collaborative tool by networking with one another. Many SLPs, school-based SLPs in particular, feel less comfortable treating stuttering than other disorders (Cooper & Cooper, 1985, 1996; Kelly et al., 1997). Moreover, in Yaruss et al.'s (2002) survey of NSA members who stutter, the respondents held a lower opinion of school-based SLPs than SLPs in other settings. Hence, school-based SLPs would likely benefit from participating in support groups, specifically by increasing their knowledge of stuttering and their comfort level with treating the disorder.

Likewise, graduate students can learn about stuttering through participating in support groups in ways not possible through traditional teaching model (Reeves, 2006). A survey of 159 ASHA accredited graduate programs and their fluency disorders requirements identified a national trend toward fewer required classes and fewer required clinical experiences (Yaruss & Quesal, 2002). As a result, there is a greater likelihood that speech-language pathology students will graduate without any clinical or academic education in fluency disorders (Yaruss & Quesal, 2002). Consequently, involvement in

stuttering support groups might be the only way some students will interact with persons who stutter.

Referral practices and incorporation into therapy

Proponents of self-help for stuttering have called for the need to examine how support groups can best be incorporated into traditional speech therapy (Yaruss et al., 2007; Ramig; 1993; Krauss-Lehrman & Reeves, 1989). Yaruss et al. (2007) suggested that clinicians should consider each of their client's goals when deciding whether and when to refer clients to support groups. Reardon and Reeves (2002) suggested referring children as a matter of standard practice after determining the level of involvement the parents and children are ready for. According to an NSA survey by McClure, D'Amico, and Tetnowski (2009), half of the SLPs affiliated with the NSA have referred PWS to the NSA's support activities, but little more if anything is known about the circumstances in which SLPs refer their clients to stuttering support groups.

Therefore, the purpose of the present investigation was to provide empirical data about the activities and perspectives of SLPs who participate in stuttering support groups and to answer the following questions:

1) How knowledgeable are SLPs about support group resources for people who stutter?

2) How often and under what circumstances do SLPs refer clients who stutter to support groups?

3) What benefits do SLPs derive from their participation in support groups for people who stutter?

4) In what capacity do SLPs prefer to participate in support groups?

An increased understanding of the support group experiences of SLPs who participate in the NSA would benefit: (1) SLPs who are looking for ways to increase their knowledge and understanding about the nature of stuttering and to reduce their lack of confidence treating the disorder, (2) students who are looking for ways to increase their knowledge of stuttering outside of the classroom and university clinic, (3) researchers examining the structure of stuttering support groups and the role SLPs play and how this dynamic fits into evidence-based practice (Reeves, 2006), (4) stuttering support groups/organizations that develop literature for clinicians, and (5) clients who stutter or parents of children who stutter (CWS) who want to be more informed consumers when looking for an SLP. In addition, the present study would add empirical support to the literature that emphasizes the partnership between stuttering self-help groups and SLPs (Reeves, 2006; Yaruss et al., 2007).

METHOD

Pilot Study

Once the initial questionnaire was complete, a group of individuals took the survey before it was sent to the main study participants. The second author sent the survey to an SLP who specializes in fluency, an adult who stutters who has been an active participant contributor to the NSA. The pilot study participants were invited to offer feedback regarding the survey. The feedback consisted of wording related considerations to a few questions. These questions were revised for clarity.

Survey Development

A 43-item survey was created to investigate SLPs' experience and opinions relating to stuttering and stuttering support groups. (See Appendix A for the complete survey). The format of the questionnaire is partially based upon the questionnaire by Yaruss et al. (2002) in which the researchers surveyed members of the NSA to learn about their experiences in speech therapy and support groups. However, the content was adapted for the present study about support group experiences of clinicians. The questionnaire included multiple choice and short answer questions.

The first questions were posed to establish the professional background of the respondents such as the number of years practicing as an SLP, clinical experience working with clients who stutter, education level of stuttering instruction, and membership in the ASHA Special Interest Division 4, Fluency and Fluency Disorders (SID-4). For those who work with clients who stutter, the next set of items asked for details about their caseload and the types of stuttering therapy they practice such as fluency shaping and stuttering modification. These items were followed by questions developed to determine the SLPs' participation levels in stuttering support groups. If

respondents reported they had participated in stuttering support groups, they were asked to indicate the different ways in which they participated such as attending a local chapter meeting and visiting the NSA's website. The next questions explored the possible benefits SLPs derive from participation in stuttering support groups. The last set of questions was designed to ascertain how often and under what circumstances SLPs refer clients who stutter to support groups.

Participants

RECRUITMENT

Subjects for the survey were drawn from the NSA's membership directory. The potential pool of participants was contacted via e-mail forwarding by NSA Executive Director, Tammy Flores. From the NSA's database of SLPs, 772 members received the survey. Of 772 e-mail messages sent, 367 (47.5%) were opened. Forty-five surveys were returned via e-mail. Therefore, the survey's return rate was 12.3% (45/367). The potential subjects received: (1) a cover letter that was approved by the authors' university Institutional Review Board as well as the NSA research committee and (2) the survey as attached Microsoft Word documents. Surveys were completed at a computer of the participants' choosing. Completing and returning the survey indicated consent to participate. Each participant was identified using an arbitrary code, which made him or her unidentifiable when referred to later. E-mail addresses were stripped from the final data set. No testing or follow-up procedures were administered.

EXCLUSIONARY CRITERIA

Reasons for exclusion included: 1) failure to complete at least 75% of the survey and 2) indication that the individual is not a member of the NSA. Three people completed less than 75% of the survey. One person indicated they were not a member of

NSA and had received the survey from a colleague. As a result, four participants were excluded from the 45 who returned the survey. This yielded 41 participants for the present study.

Current Professional Settings

31.7% (13 out of 41) indicated they currently work in a university setting; 26.8% (11) work in a private practice; 24.4% at a school; 7.3% (3) at a private practice and a school; 4.9% (2) at both a university and private practice; one person (out of 41, or 2.4%) indicated they work at a private practice, school, and a "clinic"; and another respondent (2.4%) indicated they work at school and a "long term care-skilled facility."

Previous Professional Settings

A quarter (10 out of 40) of the respondents who answered the question about previous setting, indicated they previously worked in a school setting; 10% (4 out of 40) previously worked at a university and a school; 10% (4 out of 40) worked at a private practice and school; 7.5% (3 out of 40) at a school and hospital 7.5% (3 out of 40) worked in a university setting; 7.5% (3 out of 40) worked in a private practice; 5% (2 out of 40) previously worked in a hospital; 5% (2 out of 40) university and private practice; 5% (2 out of 40) university, private practice, and a school;; 2.5% (1 out of 40) worked in a school, hospital, and "clinic"; 2.5% (1 out of 40) worked in a school, hospital, and "early intervention/nonprofit organization"; 2.5% (1 out of 40) entered "residential facility for mentally retarded" as their previous setting; 2.5% (1 out of 40) university, hospital, and other as their previous settings, but they did not specify a location for the "other" response; 2.5% (1 out of 40) private practice, school, and "rehab and nursing facility"; 2.5% (1 out of 40) inserted "federal research facility" as their previous setting; and 2.5% (1 out of 40) indicated "student" as their previous setting.

Years Practicing as an SLP

36.6% (15 out of 41) for thirty to thirty-nine years; 26.8% (11 out of 41) for twenty to twenty-nine years; 22% (9 out of 41) for ten to nineteen years; and 9.8% (4 out of 41) have been practicing between one and nine years. 4.9% (2 out of 41) have been practicing for forty to forty-nine years;

Education

68.3% (28 out of 41) indicated that they received instruction on stuttering at the undergraduate school level, and 31.7% (13 out of 41) indicated that they did not receive undergraduate instruction on stuttering. 90.2% (37 out of 41) indicated that they took at class on stuttering at the graduate school level while 9.8% (4 out of 41) did not.

Specialization

63.4% (26 out of 40) indicated that they are members of the ASHA Special Interest Division 4, Fluency and Fluency Disorders (SID4). 36.6% (15 out of 41) indicated they are not members of SID4.

Workshop attendance

Participants were asked if they have attended workshops related to fluency through any of the following organizations: ASHA, SID4, SFA (Stuttering Foundation of America). The majority of the forty respondents (40% or 16 out of 40) who answered this question indicated they have attended workshops related to fluency through all three organizations. 22.5% (9 out of 40) have attended workshops only through ASHA; 17.5% (7 out of 40) attended ASHA and SFA workshops; 12.5% (5 out of 40) attended ASHA and SID4 workshops; and 7.5% (3 out of 40) attended only SFA workshops.

Background with Clients who Stutter

All of the 41 participants indicated they have experience working with clients who stutter. When asked what type of PWS they currently work with, most participants (63.4% or 26 out of 41) indicated they work with children, teens, and adults. 14.6% (6 out of 40) work with children and teens; 14.6% (6 out of 40) work with children only; 4.9% (2 out of 40) work with teens only; and one person (2.4%) works with adults only. The numbers of clients the participants have worked with ranged from seven to over one thousand.

The percentage of the participants' caseloads that PWS constitute ranged from less than 1% to 100%. 14.6% (6 out of 41) indicated that PWS comprised 100% of their caseload. PWS constitute less than one percent of the caseload for 7.3% (3 out of 41) of the participants.

Respondents were asked to rate their level of knowledge or background in working with individuals who stutter from 1 (no knowledge) to 7 (very high level of knowledge or background). Forty of the 41 participants responded to this question. Nearly half (19 out of 40, 47.5%) rated themselves with a level 7, or the highest possible level of knowledge or background in working with individuals who stutter. Almost a third (32.5%; 13 out of 40) rated themselves as a level 6 out of 7. Five (out of 40, 12.5%) gave themselves a level 5 rating. The lowest rating any of the participants gave themselves was a level 4 (3 out of 40, 7.5%).

When asked what types of therapy they emphasize for stutter, most people (16 out of 40, 40%) indicated they use a combination of fluency shaping and stuttering modification. Seven (17.5%) of the respondents indicated they emphasize the use of the Speech Easy or delayed feedback devices in combination with other types of therapy. Five (12.5%) participants indicated they use fluency shaping, stuttering modification, and

a combination of fluency shaping and stuttering modification. None of the respondents indicated they emphasize the use of medications either alone or in combination with other types of therapy.

Regarding the types of therapy they practice with individuals who stutter, half of the respondents (20 out of 40) use a combination of group and individual therapy. Thirteen (out of 40, 32.5%) practice individual therapy only; 2 (5%) practice group therapy only; 1 (2.5%) indicated they use individual, group, and both; 1 (2.5%) indicated they use individual and both; 1 (2.5%) uses individual and "family" therapy; and 1 (2.5%) another respondent uses individual and "online individual" therapy.

Data Reduction

Data was analyzed on the basis of individual answers and without participation from the subject. Given that this is an exploratory study, a qualitative data analysis approach was employed to allow for potential identification of trends regarding support group knowledge, use, and the associated benefits. Individual and group responses to these questions were descriptively analyzed/reported to help focus the research method and design for future quantitative explorations.

Respondents were allowed to provide more than one answer for many of the questionnaire items; therefore, the percentage sum is often more than 100%. In addition, because some participants did not answer every question, the results are presented with the total number of respondents for each item.

RESULTS

The purpose of the present study was to investigate the activities and perspectives of SLPs who participate in stuttering support groups. Specifically, we explored issues such as: opinions about how responsive stuttering is to therapy, the part stuttering support groups can play in therapy, referral practices to support groups, roles SLPs play in stuttering support groups, and the benefits derived from participation in stuttering support groups. These issues were explored in comparison to professional background characteristics such as current work setting, professional experience, level of stuttering knowledge, education, caseload composition, and membership in ASHA SID-4.

How knowledgeable are SLPs about support group resources for people who stutter?

(Note that the respondents provided more than one answer for many of the items on the questionnaire; therefore, the percentages for those items add up to more than 100%.)

All of the 41 participants indicated that they are familiar with the NSA. Thirty-two (78%) of the 41 respondents indicated that they are official (i.e. due-paying) members of the NSA. Nine (22%) of the 41 participants marked that they are not official members of the NSA.

KNOWLEDGE OF LOCAL NSA CHAPTER MEETINGS

Thirty five of the 40 SLPs reporting (87.5%) knew whether or not there is a local chapter of the NSA in their hometown.

Participants who indicated there is a local NSA chapter

Over half (23 out of 40 responding, 57.5%) of the respondents indicated that there is a local chapter of the NSA in their hometown. Of the 23 SLPs who indicated there is a

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local NSA chapter in their hometown, 21 indicated they have attended a local chapter meeting. One of the two who has a local NSA chapter in their town but has not attended a meeting commented, "I haven't attended, but would like to start doing that; I need to find out when and where they meet."

Participants who indicated there is no local NSA chapter

Nearly a third of the respondents (12 out of 40; 30%) indicated that there is no local chapter in their hometown. Two of the respondents who indicated that there is no local NSA chapter commented: "I have tried to start one but the town is too small" and "I live in Canada. We have a local support group. I belong to CSA."

Participants who did not know if there was a local NSA chapter

Five (of the 40 responding, or 12.5%) did not know if there is a local chapter in their hometown. Of the five participants who did not know if there was a local chapter in their hometown, two have attended local chapter meetings in the past but elected not to answer the survey questions pertaining to local meeting experiences and possible benefits. All five said they have referred clients to the NSA. Four out of the five inform their clients who stutter about support groups as a matter of standard practice. All five participants indicated that they refer parents of children who stutter to the NSA. Two of the five said they "sometimes" recommend a client join a support group, two said they "always" recommend, and one person elected not to answer the question.

SLPS OPINIONS ABOUT THE ROLE OF SUPPORT GROUPS IN TREATMENT FOR PWS

The participants rated how strongly they believe stuttering support groups can play an important part in the therapy and recovery process for people who stutter. A majority of the respondents (29 out of 40, 72.5%) indicated that they "strongly agree" with the statement. One quarter of the respondents (10 out of 40) indicated they "agree"

that stuttering groups can play an important part in the therapy and recovery process for people who stutter. Therefore, 97.5% (39 out of 40) either strongly agree or agree that support groups are an important part of the treatment process for persons who stutter. None of the participants strongly disagreed or disagreed with the statement.

Influence of local meeting attendance on strength of agreement

A greater percentage (80%, or 24/30) of those who indicated they had attended an NSA local chapter meeting "strongly agreed" that support groups play an important role in treatment for PWS than those who had never attended a local chapter meeting (45.4%, or 5/11).

Participant who was neutral about support groups' role in treatment for PWS

Only one respondent out of forty (2.5%) indicated they were neutral to the statement that support groups can be important in the therapy and recovery process for PWS. This person indicated there is a local NSA chapter in their town, but they have not attended a meeting. In addition, they had not taken a class at the graduate school level nor were they a member of the SID-4. The individual has over 35 years' experience as an SLP, and 10% of their caseload is comprised of teens who stutter. This participant was the only person who indicated they only work with teens who stutter.

How often and under what circumstances do SLPs refer clients who stutter to support groups?

SLPs AND THEIR NSA REFERRAL

An overwhelming majority of the respondents (39 out of 40; 97.5%) indicated that they have referred clients who stutter to the NSA. One of these respondents elaborated that they "actually took 10 clients a few years ago to Chicago for the convention…great fun."

Participant who does not refer clients to NSA

Only one (2.5%) of the 40 respondents who answered this question said they have not referred clients to the NSA. However, this individual indicated on other questions that they inform clients who stutter about stuttering support groups as a matter of standard practice and that they sometimes recommend a client join a support group. Therefore, it is possible this person refers their clients to a support group other than the NSA.

REFERRAL AS STANDARD PRACTICE

Nearly all of the respondents (38 out of 39; 97.4%) inform clients who stutter about stuttering support groups as a matter of standard practice, and only one respondent (2.6%) indicated that they do not.

Participant who does not refer as a matter of standard practice

The one person who indicated that they do not inform their clients who stutter about support groups as a matter of standard practice only participates by indirect means (i.e. reading newsletters, website, and brochures) as opposed to directly attending local meetings and/or annual conferences. This individual indicated they "sometimes" recommend a client join a support group, but they do not know if there is a local NSA chapter in their town. In addition, their caseload was comprised of children only and 20% were CWS. The other attributes of the person who does not inform their clients about stuttering support groups as a standard practice were: worked in a private practice setting, had over 30 years' experience practicing as an SLP, rated themselves as having the highest level of knowledge or background in working with PWS (i.e. 7 on a scale of 1 – 7), and emphasized a combination of fluency shaping and stuttering modification techniques and family counseling.

HOW OFTEN SLPS RECOMMEND A CLIENT JOIN A SUPPORT GROUP

When asked how often they recommend a client join a support group, 23/38 (60.5%) answered "always," 14/38 (36.8%) answered "sometimes," and 1/38 (2.6%) answered "never." Of the respondents who work with children who stutter, all of them (39 out of 39 reporting) indicated that they refer children's parents to the NSA.

For those who rated the highest level of knowledge (on a scale of 1 to 7, 7 being the highest), 63% (12 out of 19) stated that they "always" recommend their clients join a support group, and 31.5% (6 out of 19) said they "sometimes" recommend a support group.

Of those who said that they "always" refer, 16 (out of 23, or 69.6%) are members of ASHA SID-4, and 7 (out of 23, or 30.4%) are not SID-4 members. Those who said they sometimes refer were nearly evenly split as members of SID-4 (8/14) and non-members (6/14).

For those with the maximal number of years of experience (over 30 years' experience), more than half (58.8%; 10 out of 17) stated that they "always" recommend, and 29.4% (5 out of 17) said they "sometimes" recommend their clients join a support group.

Participant who never recommends support groups

The participant who said they never recommend a client join a support group did indicate that they inform clients about support groups as a matter of standard practice. They specifically stated: "give info but never recommend." Additionally, this participant is a group leader for their local chapter and attends every meeting.

SLPs' OPINIONS ON BEST TIME FOR CLIENTS TO PARTICIPATE

Participants were asked when they suggest their client participate in a support group. Nearly of the respondents (38 out of 39; 97.4%) indicated that they suggest their clients participate during speech therapy. Eleven (of 39, or 28.2%) refer their clients before speech therapy, and 16 (of 39, or 41%) refer after completion of speech therapy. (Note that some respondents indicated more than one answer for this question, so the percentages add up to more than 100%.)

SLPs' OPINIONS ABOUT HOW RESPONSIVE STUTTERING IS TO TREATMENT

Participants were asked how strongly they agree with the following statement: "Stuttering is easily responsive to therapy." Fifteen respondents (out of 39, or 38.5%) indicated that they "agree" stuttering is easily responsive to therapy, 11 (28.2%) "disagree," 9 (23.1%) are "neutral," 3 (7.7%) "strongly disagree," and 1 (2.6%) indicated that they "strongly agree" with the statement. A slight majority agreed or strongly agreed with the statement (16/39), and almost as many disagreed or strongly disagreed with the statement (14/39).

Opinion about how responsive stuttering is to treatment and referral practices

Of those SLPs who "always" recommend a client join a support group, 2/23 (8.7%) "strongly disagree" that stuttering is easily responsive to therapy, 8/23 (34.8%) "disagree," 4/23 (17.4%) were "neutral," 8/23 (34.8%) "agree," and 1/23 (4.3%) "strongly agree." Of those SLPs who "sometimes" recommend a client join a support group, 1/13 (7.7%) "strongly disagree" that stuttering is easily responsive to therapy, 2/13 (15.4%) "disagree," 4/13 (30.8%) were "neutral," 6/13 (46.1%) "agree," and none "strongly agree."

SUGGESTED WAYS TO PARTICIPATE

Respondents indicated that they suggest their clients participate in support groups in several ways: 35 (89.7%) suggest they visit the NSA's web site; 31 (79.5 %) suggest they read the NSA's newsletters; 28 (71.8%) suggest they attend a local chapter meeting; 25 (64.1%) suggest they attend an annual conference; and 19 (48.7%) suggest they connect with other people who stutter via online support forums. (Note that some respondents indicated more than one answer for this question, so the percentages add up to more than 100%.)

LOCAL MEETING ATTENDANCE AND REFERRAL PRACTICES

Of those who indicated that they have attended an NSA local meeting, 20/29 (69%) "always" recommend their client join a support group, 8/29 (27.6%) "sometimes" recommend, and 1/29 (3.4%) "never" recommends (although this person said they give their clients support group information but do not specifically recommend). Of those who indicated that they have *not* attended an NSA local meeting, 3/9 (33.3%) "always" recommends their client join a support group, and 6/9 (66.7%) "sometimes" recommend.

EXPERIENCE LEVELS AND REFERRAL PRACTICES

The SLPs who "always" recommend and who "sometimes" recommend had similar experience levels. The mean number of years practicing for the "always" group was 24.2 years and for the "sometimes" group was 25.1 years.

SID-4 MEMBERSHIP AND REFERRAL PRACTICES

Those who are members of the ASHA SID-4 were more likely to indicate they "always" recommend their client join a support group (16/24 or 66.7%) than to indicate they "sometimes" recommend (8/24 or 33.3%). The same is true for non-SID-4 members but by a smaller margin: 7/14 "always" recommend vs. 6/14 "sometimes" recommend.

What benefits do SLPs derive from their participation in support groups for people who stutter?

Only those SLPs who had attended a local chapter meeting and found it valuable were asked to indicate the ways in which they found the experience helpful; whereas all SLPs were asked whether or not their NSA participation has benefited them and influenced their professional knowledge about the nature of stuttering.

BENEFITS OF ATTENDING LOCAL NSA CHAPTER MEETINGS

Respondents identified several ways in which they found their experience at an NSA local chapter meeting to be valuable. The most common benefit for the SLPs was an enhanced understanding of the thoughts and feelings of people who stutter regarding their disorder (25 out of 27, 92.6%). Nineteen out of 27 (70.4%) found that attending local NSA chapter meetings increased their comfort level working with clients who stutter; 7 (25.9%) found that it enhanced their understanding of various forms of therapy for stuttering; 5 (18.5%) found that it enhanced their understanding of the latest research regarding stuttering; 4 (14.8%) found that it is a way to gain new clients who stutter; and 3 (11.1%) found that it is a way to network with other SLPs. (Note that respondents could identify more than one answer for this question, and percentages sum to be more than 100%.)

COMMENTS ABOUT ATTENDING LOCAL NSA MEETINGS

One respondent commented, "it has offered a tremendous experience for my students to become aware of the impact of stuttering on PWS and desensitized my students to any fear of working with stuttering, a goal I am committed to." Another respondent commented, "It has enhanced my own ability to overcome adversity through the example of those that stutter. It has made me a better person, better SLP and better

mother". One individual found the experience helpful because she was able to help educate fellow members, "it was an opportunity for me to help members gain a deeper understanding of stuttering." A respondent who found value in attending a local chapter meeting did note however that, "sometimes personal agendas or opinions get in the way of the greater good."

ATTENDANCE FREQUENCY AND BENEFITS

Of those who reported how often they attended local chapter meetings, all 26 reported they found the experience beneficial including those who attend only once or twice a year (3/26, 11.5%) or less than once a year (4/26, 15.4%). This includes an individual who only attended one meeting because of geographical limitations (not living close to a local chapter meeting).

Seven of the 27 respondents (25.9%) who had attended local NSA meetings and reported the benefits wrote their own comments about the ways in which they found the experience at a local chapter meeting helpful.

OPINIONS ABOUT NSA PARTICIPATION AND EFFECTIVENESS AS A CLINICIAN

Those who have participated in the NSA were asked if they believe the experience made them a more effective clinician. Twenty (out of 37 responding, 54.1%) indicated they "strongly agree," 13 (35.1%) "agree," 3 (8.1%) are "neutral," and 1 (2.7%) indicated that they "disagree" with the statement. The respondent who does not agree that NSA participation made them a more effective clinician indicated there is no local chapter of the NSA in their hometown, and they did not return after their first meeting.

Influence of local NSA meeting attendance on SLPs' opinion

Of the SLPs who attended every local NSA meeting or every other meeting (i.e. frequent attendees) 11 (out of 17 responding, or 64.7%) "strongly agree" and 6 (out of 17

responding, or 35.3%) "agree" that their participation has made them a more effective clinician. Of the clinicians who indicated that they attend once or twice a year or less than once a year (i.e. infrequent attendees) 4/7 (57.1%) "strongly agree," 1/7 (14.3%) "agree," 1/7 (14.3%) was "neutral," and 1/7 (14.3%) "disagreed" that their participation has made them a more effective clinician.

OPINIONS ABOUT NSA AS A UNIQUE LEARNING OPPORTUNITY

Next, those who have participated in the NSA were asked if they agreed with the following statement: "what I learned through my involvement in the NSA, I did not learn in school." More than half of the respondents (19 out of 37; 51.4%) indicated they "strongly agree," nearly a third (13 out of 37; 35.1%) "agree," 3/37 (8.1%) are "neutral," and two (5.4%) "disagree."

Influence of local NSA meeting attendance on SLPs' opinion

Of the SLPs who attended every local NSA meeting or every other meeting (i.e. frequent attendees) 10/17 (58.8%) "strongly agree," 5/17 (29.4%) "agree," 1/17 (5.9%) was "neutral," and 1/17 (5.9%) "disagreed" that what they learned through their involvement in the NSA was not something they learned in school. Of the clinicians who indicated that they attend once or twice a year or less than once a year (i.e. infrequent attendees) 3/7 (42.8%) "strongly agree," 1/7 (14.3%) "agreed," 2/7 (28.6%) were "neutral," and 1/7 (14.3%) "disagreed" that what they learned through their involvement in the NSA was not something they learned in school.

OPINIONS OF MEMBERS OF SID-4 WHO HAVE PARTICIPATED IN NSA

The respondents who have received specialized training in fluency disorders and participated in the NSA were asked if what they learned through the NSA was uniquely valuable to their understanding and competence working with clients who stutter.

Almost half of the respondents (17 out of 35; 48.6%) indicated they "strongly agree," 12 (34.3%) "agree," 3 (8.6%) are "neutral," and 2/35 respondents (5.7%) "disagree" with the statement. One of the two who did not agree that the NSA was uniquely valuable nevertheless "strongly agreed" that the NSA made them a more effective clinician. And both of these individuals indicated that they derived value from their involvement with the NSA. In lieu of rating their agreement level with the statement, one respondent made the following comment, "Wish I had received more training; I'm looking to find inexpensive ways to do so. Will be attending conference in Ft. Worth with one of my clients and her mother."

Influence of local NSA meeting attendance on SLPs' opinion

Of the clinicians who were frequent attendees at local NSA meetings, 8/15 (53.3%) "strongly agree," 6/15 (40%) "agree," and 1/15 (6.7%) "disagreed" that what they learned through their involvement in the NSA was uniquely valuable to their understanding and competence working with clients who stutter. Of the SLPs who were infrequent attendees, 4/7 (57.1%) "strongly agree," 1/7 (14.3%) "agree," 1/7 (14.3%) was "neutral," and 1/7 (14.3%) "disagreed" that what they learned through their involvement in the NSA was uniquely valuable.

In what capacity do SLPs prefer to participate in support groups?

PARTICIPATION ACTIVITIES

Respondents indicated more than one answer for this question; therefore the sum of percentages exceeds 100. The two most common ways in which the SLPs participate in the NSA are reading the NSA's newsletters (39 out of 41; 95.1%) and visiting the NSA's website (39/41; 95.1%). Thirty-six (87.8%) of the respondents have read brochures or other literature produced by the NSA, 30/41 (73.2%) have attended an NSA

local chapter meeting, 27/41 (65.9%) have attended an NSA annual conference, 20/41 (48.8%) have participated in online support groups (e.g. STUTT-L or the stutteringchat Yahoo! group), 20/41 (48.8%) have participated in the NSA's Continuing Education workshops, and 17/41 (41.5%) have attended an NSA Youth Day or regional workshop. Nine out of the 41 (22%) participants indicated that they participated in all eight ways. Six of the 41 respondents (14.6%) have not attended an NSA event or meeting but have read the newsletters, visited the website, and read brochures. Three of the respondents (7.3%) have participated in all ways except attending an NSA Youth Day or regional workshop and participating in Continuing Education workshops.

HOW LOCAL MEETING ATTENDEES FIRST HEARD ABOUT THE NSA CHAPTER

Regarding how they first heard about the local chapter, over a third (9/26, 34.6%) of the respondents indicated that they started their local chapter, 4 (15.4%) heard about their local chapter from a colleague, 4/26 (15.4%) learned about their local chapter from the NSA, 3/26 (11.5%) heard through one of their clients, 1/26 (3.8%) heard through the web, 1/26 (3.8%) heard through the Stuttering Foundation of America, 1/26 (3.8%) heard through their university where they studied speech pathology, 1/26 (3.8%) indicated they are the faculty advisor to local NSA which meets at their university, 1/26 (3.8%) said their speech therapist referred them, and 1/26 (3.8%) was referred by a graduate student they were supervising.

Twenty-four of 25 respondents (96%) indicated that they returned after their first local chapter meeting. The one person who did not return said they do not live nearby but "attend other self help."

NUMBER OF YEARS PARTICIPATING IN LOCAL MEETINGS

The respondents who attended a local support group meeting were asked how long they have been participating. Ten of the twenty-two (45.5%) who answered this question have been going to their local meeting between 1 and 4 years, 6 (27.3%) have been attending between 10 and 20 years, 4 (18.2%) have been attending between 5 and 9 years, and 2 (9.1%) have been attending for more than 20 years.

FREQUENCY OF ATTENDANCE

Most (16 out of 25; 64%) of the SLPs who attended local chapter meetings indicated that they are present at every meeting. Four respondents (16%) indicated they attend less than once a year. Three respondents (12%) indicated they attend once or twice a year. Two respondents (8%) attend every other local chapter meeting.

ROLE IN LOCAL MEETINGS

When asked what type of role they played in a local support group, twenty-six participants responded. The most common role respondents indicated they played was presenter/facilitator (19/26) followed by the roles of group leader (17/26), and regular attendee (10/26). Participants were allowed to mark more than one role since many do in fact play more than one role in their local NSA chapter meetings.

Viewing the data another way, 7 (of the 26 responding, or 26.9%) indicated that they play all three roles in their local support group: regular attendee, presenter/facilitator, and group leader. Another 7 (26.9%) respondents indicated they are presenters/facilitators only. Six (23.1%) respondents are group leaders only. Three respondents (11.5%) play the role of presenter/facilitator and group leader. Two respondents (7.7%) indicated they are regular attendees and presenters/facilitators. Only

one (3.8%) of the twenty-six who responded to this item indicated that they are both a regular attendee and a group leader.

SLPs' RECEPTION AT LOCAL MEETINGS

Next the respondents were asked to rate their agreement level of the statement: "As a speech-language pathologist, I felt welcome at the meeting." Most of the respondents (68%; 17 out of 25) indicated that they "strongly agree" with the statement. Seven of the 25 respondents (28%) indicated they "agree" that as SLPs they felt welcome at their local chapter meeting. One respondent (2.3%) indicated they were "neutral." None of the respondents disagreed or strongly disagreed with the statement.

SLPs' OPINIONS ON TAKING LEADERSHIP ROLES IN LOCAL CHAPTERS

Thirty-nine respondents expressed their opinions about SLPs taking leadership and facilitating roles in support groups. Nearly half of the respondents (48.7%; 19 out of 39) believe SLPs should take a role in leading and facilitating support groups, and almost as many (43.6%; 17 out of 39 respondents) indicated that SLPs should "maybe" lead and facilitate support groups. Far fewer respondents (7.7%; 3 out of 39) believe that SLPs should not lead or facilitate support groups for PWS. Two of the people who responded "maybe," elaborated on their conditional answer. One person commented that SLPs should lead or facilitate support groups "only if the SLP has solid knowledge about the nature and current treatment of stuttering." Another participant believes that the answer "depends on what the support group needs for the group."

ANNUAL CONFERENCE ATTENDANCE AND PARTICIPATION

Twenty-one respondents provided the year they first attended an NSA annual conference, while 5 people indicated that they were unsure of the year. Among the 21 who answered with a specific year, the most frequent responses were 1997 (4 out of 21;

19.05%) and 2010 (4 out of 21; 19.05%). Twelve people (of 21, or 57.1%) attended their first conference between 1989 and 1999, and 9 people (42.9%) first attended between 2000 and 2010.

Twenty-four respondents indicated how many NSA annual conferences they have attended. Eleven people (out of 24 responding, or 45.8%) have attended between 2 and 5 times. One third of the respondents have been once (33.3%, 8 out of 24). Five (20.83%) have attended more than 5 times.

When asked how often they attend an NSA annual conference, most respondents (14 out of 19; 73.68%) said they go "every few years." Fewer respondents go "every other year" (2 out of 19, 10.53%) or "every year" (2 out of 19, 10.53%). One person (out of 19 responding, 5.26%) commented that they attend when they can.

Regarding how they participated in the NSA annual conference, all of the respondents (out of 26 responding) attended workshops, most (19 out of 26, 73.08%) gained continuing education certification, 9 (34.62%) hosted a workshop, and 2/26 (7.69%) presented research.

DISCUSSION

To review, the purpose of this study was to determine the role and perspective of SLPs with respect to support groups for people who stutter. The present study is an early step in the process of establishing empirical support for the benefit regarding the partnership between SLPs and support groups for people who stutter. These preliminary data suggest the majority of SLPs who are current or former members of the NSA refer their clients to meetings and also derive personal benefits from their own involvement in the organization. Due to the self-selected nature of the participants in the current study, the survey results do not represent all SLPs who treat PWS. The following discussion is organized relative to responses to the major research questions that were explored.

How knowledgeable are SLPs about support group resources for people who stutter?

It is not surprising that all of the participants in the study were familiar with the NSA because the participants come from the NSA's membership directory. Over three quarters of the participants were official, due-paying members of the NSA. Most of the SLPs knew whether or not there was a local chapter of the NSA in their hometown. The five SLPs who did not know if there was a local chapter in their town indicated that they have referred clients who stutter to the NSA and indicated that they referred parents of children who stutter to the NSA. All five either agreed or strongly agreed that stuttering support groups can play an important part in the therapy and recovery process for people who stutter. Interestingly, only one of the five indicated they suggest their clients attend local chapter meetings, but this person has never attended a local meeting himself or herself. This individual did, however, attend an annual conference. The two who had attended local meetings were the two who always recommend their clients join a support

group. Most of the SLPs who were unaware of a local chapter nevertheless suggested their clients participate by attending an annual conference, reading NSA's newsletters, and/or visiting the NSA's website. Therefore, it is possible that these clinicians would recommend their clients attend a local meeting if they were aware of a local chapter in their hometown.

How often and under what circumstances do SLPs refer clients who stutter to support groups?

All of the participants said they have either referred clients to the NSA or have recommended a client join a support group. In addition, almost all of the SLPs suggest their client participate in a support group concurrently with their speech therapy.

Only one participant indicated that they do not inform their clients who stutter about support groups as a matter of standard practice. A possible explanation is that this individual has not experienced any benefits from support groups since they have never directly attended local chapter meetings or annual conferences and have only participated by indirect means (i.e. reading newsletters, website, and brochures). Another possible reason they do not inform clients as a standard practice is that they treat children exclusively. To date, no empirical studies have explored the benefit of stuttering support groups for children (Yaruss et al., 2007). Despite the fact they do not recommend support groups as standard practice and they do not know if there is a local NSA chapter in their town, this individual did indicate they refer parents to the NSA and they sometimes recommend a client join a support group.

The SLPs who have attended local NSA meetings were more likely to always recommend their client join a support group than those SLPs who have never attended a local NSA meeting. Therefore, participation in local NSA meetings appeared to

influence the clinicians' recommendation practices. However, there was an SLP who indicated that they never recommend their clients join a support group. This individual reported they were a group leader for their local chapter, and they inform their clients who stutter about support groups as a matter of practice. Thus, it is possible this clinician prefers to provide the information about support groups to their clients but let them come to their own conclusions about joining a group.

Further support for the influence of attendance on clinical practice is found in our results that showed that three quarters of the SLPs strongly agree that support groups are a valuable component of recovery for PWS but those SLPs who had attended an NSA local chapter meeting were more likely to strongly agree that support groups are important in treatment than those who had never attended a local meeting.

Only one participant was neutral to the statement that support groups can be important in the therapy and recovery process for PWS. This individual's professional background may account for their opinion about support groups' role in therapy as they indicated the following: there is a local NSA chapter in their town, but they had not yet attended a meeting; they were not a member of SID-4; they did not take a fluency class at the graduate school level; they have practicing over 35 years as an SLP; and was the only participant whose clients who stutter are exclusively teens. Perhaps there is something unique about working with the population of teens who stutter that makes stuttering support groups seem less important to the therapy and recovery process. However, it is more likely that the participant's lack of attendance at any meeting precludes him/her from seeing the value of support group participation.

In his 2006 article, Reeves referenced studies reporting that many SLPs did not view stuttering as easily responsive to therapy. The SLPs surveyed in this study had varied opinions about this topic. They were almost evenly split in agreement and

disagreement, therefore for this group of SLPs, their feelings about stuttering's responsiveness to therapy did not appear to influence their level of involvement in support groups nor their referral decisions. Furthermore, the number of years practicing as an SLP did not appear to influence the recommendation practices of the participants.

What benefits do SLPs derive from their participation in support groups for people who stutter?

Although all SLPs who attended local meetings found the experience beneficial, those who attended more frequently were more likely to "strongly agree" or "agree" that NSA participation: (1) made them a more effective clinician, (2) taught them something that they did not learn in school, and (3) learned something through the NSA that was uniquely valuable to their understanding and competence working with clients who stutter. Interestingly, the two participants who did not agree that their involvement in the NSA taught them something they did not learn in school both have 20 years' experience as SLPs, had both undergraduate and graduate courses in fluency, and are members of SID-4.

Several studies have documented the fact that many SLPs are less comfortable treating fluency disorders than other types of communication disorders (Cooper & Cooper, 1985, 1996; Kelly et al., 1997; (Yaruss et al. 2007). Most of the participants in the present study increased their comfort levels working with PWS by attending local support groups. Additionally, almost all of the clinicians who attended local NSA chapter meetings derived an enhanced understanding of the thoughts and feelings of PWS regarding the nature of stuttering. Thus, clinicians who would like to increase their

comfort level with treating stuttering and enhance their knowledge of the disorder, there is now empirical evidence that attending local support groups can help.

In what capacity do SLPs prefer to participate in support groups?

The two most common ways SLPs chose to participate in support groups were indirect in nature: reading the NSA's newsletters and visiting the NSA website. Nevertheless, almost three quarters of the participants have attended a local NSA meeting, and two thirds have attended an NSA annual conference. Over a fifth of the respondents have participated in all eight NSA activities that were listed on the questionnaire.

When asked whether or not they felt welcome at an NSA local chapter meeting, one clinician "strongly agreed" that they felt welcome. However, this individual added that they did not feel welcomed back in 1982 when they first attended, and that "it took several years to really be accepted by the group."

Over a quarter of the participants play three roles in their local NSA meetings: regular attendee, presenter/facilitator, and group leader. Consequently, it is not surprising that when asked where they first heard about the local meetings over a third said they had started their own local chapter. A different quarter of respondents said they were presenter/facilitators at their NSA local chapter meetings. The data from this study demonstrates that clinicians are taking active roles in their local stuttering support groups. Furthermore, most of the SLPs who attend local meetings are present at every meeting. Most of these SLPs have been attending their local support meetings between five and twenty plus years.

Limitations

One of the limitations of the present study was that the questionnaire did not inquire about the possible benefits from other types of participation than just local chapter meetings. It would be worthwhile to investigate whether those who participate through indirect means (e.g. reading newsletters, visiting the NSA website, participating in online forums, etc.) derive the same benefits as those who participate via direct means (i.e. local NSA chapter meetings).

Another possible limitation is the low response rate of the survey (12.3%, or 45/367). Of 772 e-mail messages sent, 367 (47.5%) were opened. Forty-five surveys were returned via e-mail. While the low response rate may indicate a biased sample, this study provides the first empirical evidence detailing the roles and perspectives of clinicians with respect to stuttering support groups.

Future directions

Future analysis of the partnership between SLPs and stuttering support groups could include those SLPs who are not members of NSA and graduate students in speech-language pathology programs. A survey could investigate whether or not most SLPs at least have an awareness of support groups for PWS. More research is needed to fine-tune the best circumstances under which to refer clients to support groups. As noted above, a future investigation could examine the possible benefits for those SLPs who do not participate in support groups directly (not attending meetings, only visiting website, reading brochures, etc.). After acknowledging the high level of involvement and rate of referrals by SLPs, future research could also investigate the theory that stuttering support group organizations would not have grown at such a rapid rate were it not for SLPs referring their clients to the self-help group and also actively participating.

Conclusion

In sum, the present study revealed that clinicians overwhelmingly believed their participation in stuttering support groups had a positive effect. In addition, nearly all of the SLPs agreed that stuttering support groups are an important element in the therapy and recovery process for PWS. The only person who was neutral about the role of support groups in the recovery process for PWS is someone who chooses not to attend local chapter meetings despite the availability of one. All SLPs who attended local support group meetings found the experience beneficial regardless of how often they attended. However, those who attended more frequently were more likely to agree that NSA participation made them a more effective clinician and taught them something that was uniquely valuable to their understanding and competence in working with their clients who stutter.

APPENDIX

Survey for SLPs regarding participation in stuttering support groups

Instructions: Please complete the following survey as thoroughly as possible. Except where otherwise indicated, check all answers that apply.

PROFESSIONAL BACKGROUND

1. In what professional setting/s do you currently work? __University __Private practice __School __Hospital

   __Other (please specify)

2. In what professional setting/s did you previously work? __University __Private practice __School __Hospital

   __Other (please specify)

3. How many years have you been a practicing SLP? _____

4. Do you have any clinical experience working with clients who stutter? __ Yes __ No

5. Please rate your level of knowledge or background in working with individuals who stutter? (1=no knowledge or background to 7= very high level of knowledge or background).

   1   2   3   4   5   6   7

6. Did you receive instruction on stuttering at the undergraduate school level?
   __ Yes __ No

7. Did you take a class on stuttering at the graduate school level?
   __ Yes __ No

8. Are you a member of the ASHA Special Interest Division 4, Fluency and Fluency Disorders?
   __ Yes __No

9. Have you attended workshops related to fluency through any of the following organizations? (check all that apply)
   __ ASHA
   __ SID4
   __ SFA (Stuttering Foundation of America)

10. If you work with clients who stutter:

    a. What type of PWS do you work with? __ Children __ Teens __ Adults

    b. How many people who stutter have you worked with (please provide number)?

_____ Children _____ Teens _____ Adults

    c. What percentage of your caseload do people who stutter constitute? _____

    d. What types of therapy do you emphasize for stutter?
        __ Fluency shaping
        __ Stuttering modification
        __ Combination of fluency therapy and stuttering modification
        __ Use of medications
        __ Use of the Speech Easy or delayed feedback devices
        __ Other. Please specify. _____

    e. What types of therapy do you practice with individuals who stutter?
        __ Group therapy
        __ Individual therapy
        __ Both group and individual therapy
        __ Other

STUTTERING AND STUTTERING SUPPORT GROUPS:

1. Stuttering is easily responsive to therapy. How strongly do you agree with this statement?

    1 – strongly disagree   2 – disagree   3 – neutral   4 – agree   5 – strongly agree

2. Do you believe stuttering support groups can play an important part in the therapy and recovery process for people who stutter?

    1 – strongly disagree   2 – disagree   3 – neutral   4 – agree   5 – strongly agree

3. Are you familiar with the National Stuttering Association?   __Yes
    __ No

4. Are you an official (i.e., due-paying) member of the NSA?   __Yes
    __ No

5. In what ways have you participated in stuttering support groups?
        __ I have attended an NSA local chapter meeting
        __ I have attended an NSA Youth Day or regional workshop
        __ I have attended an NSA annual conference
        __ I have participated in the NSA"s Continuing Education workshops
        __ I read the NSA's newsletters
        __ I have visited the NSA's Web site
        __ I have read brochures or other literature produced by the NSA
        __ I have participated in online support forums (e.g. STUTT-L or the stutteringchat Yahoo group)

6. Is there a local chapter of the NSA is your hometown?
   __Yes   __No __Don't know

7. If you have attended a local support group meeting:
   a. How did you first hear about the local chapter?
      __Through a colleague
      __Through one of my clients
      __Through the Web
      __Through ASHA
      __Through the Stuttering Foundation of America
      __Through my university where I studied speech pathology
      __Other. Please specify _____

   b. Did you return after your first meeting?
      __ Yes __ No

   c. For how long in years and months have you been participating in local chapter meetings? _____

   d. If you did NOT return after your first meeting, please explain why

      _____

      _____

   e. How often do you attend the local chapter meetings
      __ Every meeting __ Every other meeting __Once or twice a year __Less than once a year

   f. What role/s have you played in a local support group?
      __ Regular attendee
      __ Presenter/facilitator
      __ Group leader

   g. As a speech-language pathologist, I felt welcome at the meeting.
      1 – strongly disagree   2 – disagree   3 – neutral   4 – agree   5 – strongly agree

   h. If you found your experience at a local chapter meeting valuable, in what ways did you find it helpful?
      __ It has enhanced my understanding of the latest research regarding stuttering
      __ It has enhanced my understanding of the various forms of therapy for stuttering
      __ It has enhanced my understanding of the thoughts and feelings of people who stutter regarding their
         disorder
      __ It has increased my comfort level working with clients who stutter
      __ It is a way to gain new clients who stutter
      __ It is a way to network with other SLPs
      __ Other. Please specify
      _____
      _____

i.   If the experience of attending a local chapter meeting was not valuable to, why was it not?

__

__

__

__

8. Do you think SLPs should take a role in leading and facilitating support groups?
    __Yes   __No __Maybe

9. Have you referred clients who stutter to the NSA?
    __Yes   __No

10. Do you inform clients who stutter about stuttering support groups as a matter of standard practice?
    __Yes   __No

11. If you work with children who stutter, do you refer their parents to the NSA?
    __Yes   __No

12. If you refer clients who stutter to support group meetings:
    a. When do you suggest they participate in a support group?
        __ Before speech therapy __ During speech therapy __ After completion of speech therapy

    b. How often do you recommend a client join a support group?
        __ Always __ Sometimes __Never

    c. In what capacity do you suggest they participate?
        __ Attend a local chapter meeting
        __ Annual an annual conference
        __ Read the NSA's newsletters
        __ Visit the NSA's Web site
        __ Connect with other people who stutter via online support forums

13. If you have attended an NSA annual conference:
    a. When did you attend your first conference? _____
    b. How many conferences have you attended? _____
    c. How often do you attend a conference? __ Every year __ Every other year __ Every few years
    d. In what capacity did you participate in the conference?
        __ I attended workshops
        __ I gained CE certification
        __ I hosted a workshop
        __ I presented research

14. If you have participated in the NSA, do you believe this experience has made you a more effective clinician?

   1 – strongly disagree   2 – disagree   3 – neutral   4 – agree   5 – strongly agree

15. If you have participated in the NSA, do you agree with the following statement? What I learned through my involvement in the NSA, I did not learn in school.

   1 – strongly disagree   2 – disagree   3 – neutral   4 – agree   5 – strongly agree

16. If you have received specialized training in fluency disorders and participated in the NSA, was what you learned through the NSA uniquely valuable to your understanding and competence working with clients who stutter?

   1 – strongly disagree   2 – disagree   3 – neutral   4 – agree   5 – strongly agree

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