Self-Help Conferences and Change in the Experience of Stuttering:
Preliminary Findings and Implications for Self-help Activities

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Abstract. Participants (n=117) of a national conference for people who stutter (PWS) completed the Overall Assessment of the Speaker's Experience of Stuttering for Adults (OASES; Yaruss & Quesal, 2008) at the beginning of a self-help conference (SHC) and 4 - 6 months after a SHC. Results indicated changes in their overall experience of stuttering for a majority of participants after the conference. The largest changes in impact scores were seen in participants who had never attended or were relatively new to the SHC. This supports the notion that self-help activities can play a role in the overall management of stuttering. Practical implications include detail about the underutilization of self-help activities and ways that accessibility has increased through online self-help resources for PWS.

1. Background for Successful Stuttering Management and Self-help Activities

Studies about successful stuttering management and maintainence, often include discussion about: improving quality of life, decreasing fears of speaking, and talking with other people who stutter (DiLollo, Neimeyer, & Manning, 2002; Plexico, Manning and DiLollo, 2005). People who attend self-help activities for people who stutter (PWS) such as self-help groups, self-help workshops, and self-help conferences (SHC) often report that attendence at these activities to be beneficial. Qualitative studies have found that self-help groups for PWS (Boyle, 2013; and Trichon, Tetnowski, & Rentschler, 2007) and SHC for PWS (Trichon &Tetnowski, 2011) to be beneficial. A suvery study also found that PWS who attend self-help groups and/or self-help conferences to be beneficial (Tetnowski & McClure, 2009).

Narratives of 12 PWS who attend SHC (Trichon, 2010), reveal a wide range of emotions (i.e. embarrassment, fear, frustration, loneliness, and shame) and domains within their lives (i.e. personality, bullying/teasing, education, dating, career choice/advancement, work performance, and perception of others) that have been impacted by stuttering. Other studies of a broader population of PWS (not specific to the self-help community of PWS) coincide with these finding to show that as a group, PWS who attend SHC, experience stuttering in a similar way that the greater population of PWS experience stuttering (Anderson & Felsenfeld, 2003; Corcoran & Stewart, 1998; Crichton-Smith, 2002; Finn, 1997; Hayhow, Cray, & Enderby, 2002; Hugh-Jones & Smith, 1999; Klompas & Ross, 2004; Plexico, Manning, & DiLollo, 2005; Sheehan, 1970; and Tangney, Miller, Flicker, & Barlow, 1996).

Despite a growing number or studies that support the role of self-help activites in the management of stuttering self-help activities remain an underutilzed resource for PWS. Reasons for this include lack of professional referrals, possibly due to a scarcity of research, especially ones that use familiar instruments.

The purpose of this study was to use a commonly-used, widely-accepted questionnaire to evaluate the relationship between attending self-help conferences for PWS and its impact on their experience of stuttering. The following research questions were asked:

A. Is there a difference between pre- and post- self-help conference (SHC) scores on the Overall Assessment of Speaker's Experience of Stuttering (OASES; Yaruss & Quesal, 2008) for people who stutter (PWS) that attend a self-help conference?
B. Is there a difference in pre- and post-SHC scores on the OASES for PWS that attended: (a) one conference, (b) a few conferences (2-4), (c) several conferences (5-8), or (d) many conferences (9+)?
C. Is there a statistically significant interaction between pre- and post-SHC OASES scores based upon conferences attended?

2. Methodology

In this study, a widely recognized assessment tool, the Overall Assessment of the Speaker's Experience of Stuttering for Adults (OASES; Yaruss & Quesal, 2008), was used to explore the potential impact that attending self-help conferences had on changes in the overall speaker's experience of stuttering, for adults. The test uses a 5-point (5), equally appearing, interval scale, for each of its 100 items. There is an impact score for each of the four subtests and an overall (total) impact score. The subtests are: a) General Information, b) Reactions to Stuttering, c) Communication in Daily Situations, and d) Quality of Life.

Sample Question:
5) How often do you say exactly what you want to say even if you think you might stutter?

① ALWAYS ② OFTEN ③ SOMETIMES ④ RARELY ⑤ NEVER

With the co-operation and approval of the National Stuttering Association Research Committee and the co-operation of Friends-The Stuttering Association of Young People Who Stutter, 150 participants who attended one of the two organizations' national SHC, who self-identify as an adult who stutters, completed a questionnaire booklet which included a version of the Overall Assessment of the Speaker's Experience of Stuttering (OASES; Yaruss & Quesal, 2008) before (or at the beginning) of a SHC and again 4 - 6 months after the SHC. Other data collected that was pertinent to this study included the number of SHC attended by the participant.

There were 117 participants who completed both pre- and post-OASES tests and were therefore eligible for inclusion in the analysis. Incomplete OASES scores were not included. Five, 2 x 4 repeated measures ANOVA were calculated on the variables of interest. The following table shows the basic design:

Conf. Attended	1 Conference		2-4 Conferences		5-8 Conferences		9+ Conferences	
___-Conf.	Mean	SD	Mean	SD	Mean	SD	Mean	SD
PRE								
POST								

The assumptions of a repeated measures ANOVA were tested a priori. Two within subject variables are categorical in nature. There is one interval or ratio dependent variable. No major impact of outliers of the residuals. Normality of distribution within groups (test is robust for violations). Assumption met in all cas es. There was one outlier in the 5-8 Conferences group. The data was run using two ways with no difference. Residuals were tested looking for <3 SD. Normality tested with Shapiro-Wilk (p > .05). Homogeneity of variances were tested through Mauchley's test of Sphericity (p > .05).

3. Results
The scores of each subtest and overall (total) score were totaled and divided by the number of items responded to by each participant. The means and standard deviations were calculated from the various impact scores of eligible participants.

Subtest #	Conf. Attended / ___- Conf.	1 Conference		2-4 Conferences		5-8 Conferences		9+ Conferences	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
1 - General Information	PRE	2.72	0.61	2.51	0.62	1.99	0.56	1.75	0.72
	POST	2.51	0.57	2.45	0.60	1.98	0.66	1.76	0.68
2 - Reactions to Stuttering	PRE	3.04	0.67	2.51	0.62	2.42	0.53	2.29	0.72
	POST	2.74	0.63	2.45	0.60	2.41	0.53	2.28	0.67
3 - Communication in Daily Situations	PRE	2.67	0.77	2.39	0.54	2.44	0.76	2.09	0.70
	POST	2.59	0.68	2.37	0.55	2.43	0.65	2.13	0.68
4 - Quality of Life	PRE	2.45	0.90	1.98	0.81	1.99	0.56	1.75	0.72
	POST	2.21	0.89	1.95	0.79	1.98	0.66	1.76	0.68
Overall (TOTAL)	PRE	2.73	0.61	2.18	0.69	2.28	0.56	2.07	0.59
	POST	2.51	0.57	2.20	0.54	2.28	0.55	2.08	0.55

Based on these results, five, 2 x 4 repeated measures ANOVA were calculated on the variables of interest – the various impact scores of the OASES and the number of SHC attended. The results helped to answer the research questions:

A. Is there a difference between pre- and post- SHC scores on the OASES for PWS that attend a self-help conference?
No
B. Is there a difference in pre- and post-SHC scores on the OASES for PWS that attended: (a) one conference, (b) a few conferences (2-4), (c) several conferences (5-8), or (d) many conferences (9+)?
Yes
C. Is there a statistically significant interaction between pre- and post-SHC OASES scores based upon conferences attended?
No

4. Conclusion and Discussion
A. Research Implications
There was no main effect between pre-conference and post-conference scores. Possible explanations include: there is no effect pre- versus post-conference, the effect wears off in less than the 4 - 6 month interval used in this study, the effect takes longer to have an impact than the 4 - 6 month interval used in this study, and the changes that take place are not "measurable" by the OASES.

Not all subtests of the OASES trend in the same direction. For example, General Information does not show a statistically significant difference until a PWS attends at least "a few" conferences (2-4) and Communication in Daily Settings does not show a statistically significant difference until the person attends "many" conferences (9+).

B. Limitations of the Study
Limitations of the study include: that there was no control group of PWS that did not attend a SHC during the same time-frame the sample group and that there was no controlling for potential contributing factors to participants' experience of stuttering, either before or after the SHC (e.g. pre- or post-conference therapy of any kind or participation in any other self-help activities, etc.).

It should also be recognized that people's experience of self-help conferences vary due to logistical factors and personal factors. Logistical factors include: conference location, variation in conference workshops (e.g. workshops offered year-to-year, workshop speakers, workshop attendees/participants), planned and unplanned social events, and participants at social events. Personal factors include: how past experiences shape the perception, who the attendee brings with them, workshops attended, and who attendees meet and spend time with while at the conference.

C. Future Research
These results lead to further questions in this domain. Potential areas of future research include to: investigate the early impact of going to a SHC (e.g., pre-, 2 weeks-post, 1 month-post, 3 month-post), investigate the late or longer lasting impact of attending a SHC (e.g. pre-, 9 months-post, 1 year-post, 2 years-post, etc.), investigate only first-time attendees pre- vs. post-SHC, investigate the effects of attending a SHC by tools other than OASES (e.g. qualitative methodologies such as: ethnography, narrative, phenomenology, or other quantitative tools), investigate potential factors which may have affected the results (e.g. workshops attended or types of socializing by attendee), investigate the impact of attending a SHC for teenagers and/or for school-age children, and to investigate other self-help activities for PWS including in-person activities and online activities.

D. Underutilization of Self-help Activities

Despite the evidence to support the benefits of self-help activities for PWS they have been an underutilized resource. As previously mentioned, one major factor is the lack of referrals from professionals who may not know of the existence of self-help activities or of the literature to support their utility. Despite the research professionals may differ in their approach to stuttering treatment. Another factor is the lack of knowledge of the existence of self-help activities by PWS, family members, or professionals (previously mentioned). Those who are aware may still not attend due to the fact that there may also be a lack of willingness to attend/participate due to shame, embarrassment or not wanting to feel like they have 'give-up' by identifying with other PWS. Last of the major factors is the lack of accessibility to self-help activities. Distance to self-help activities may be prohibitive because attending could take too much time, cost too much money, or may not be possible since some do not have the transportation to attend, especially for those who have mobility or other health issues unrelated to stuttering. Accessibility, however, has improved for people who have internet access because of the existence of online self-help activities for PWS.

E. Online Self-help Activites for PWS
Online self-help activities have improved accessibility for self-help activities for those with internet access, but this does not negate the accessibility issue for those who do not have internet access or those who prefer in-person activities who live too far from the limited locations of in-person self-help activities.
    Numerous studies have recognized that the internet has brought about a number of ways for self-help activites to exist online for PWS (Bloodstein & Ratner, 2008; Bloom & Cooperman, 1999, Ramig & Dodge, 2005, Reeves, 2006; Reitzes & Snyder,

2009; Starkweather & Givens-Ackermann, 1997; Tetnowski, Osborne, & Trichon, 2011). Research in this realm of online, self-help for PWS has also shown positive benefits. (Raj, 2015; Raj & Daniels, 2013). More research is needed in this area.

Some of the current self-help activities that exist online for PWS include the following: discussion groups (e.g. Stutt-L, Covert-S, podcasts (e.g. StutterTalk, Women Who Stutter, Stuttering is Cool), blogs (e.g. Make Room for the Stuttering, Diary of a Stutterer), social networking websites (e.g. Facebook groups such as Stuttering Community and Stuttering Arena (Trichon, 2010), video conferencing community websites (e.g. Stutter Social) and smartphone applications that have also been specifically developed to facilitate communication between PWS (e.g. Stutter Social).

Stutter Social, which formed in 2011, is an organization that has built a video conferencing community website and a smartphone application to facilitate online self-help activities for PWS. A video conferencing platform (i.e. Google Hangouts) to host serval self-help group meetings per week. Participants are able to interact with each other through video and microphone through a computer or mobile device. Participants from over 35 countries have participated in their video conferencing community. In 2015, they released their smartphone application to provide a dedicated social networking application just to communicate with other PWS. This provides protection for the community from people with ulterior motives and more privacy protection.

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