The utility of stuttering support organization conventions for young people who stutter

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ARTICLE INFO

ABSTRACT

Background: Stuttering Support Organizations (SSOs) are places where people who stutter can share their experiences with stuttering and lend support to each other. There is evidence that SSO participation may be helpful in reducing the negative impact of stuttering and promoting positive cognitive and affective changes in adults who stutter. The benefits of participating in SSO organizations for young people, however, are currently unknown.
Purpose: This study investigated the relationship between attending a multi-day SSO convention and cognitive and affective changes among young people who stutter (YPWS).
Methods: Twenty-two YPWS (ages 10 to 18) were recruited from the 2016 FRIENDS annual convention to participate in this study. FRIENDS is the National Association of Young People Who Stutter. A mixed methods approach was used to collect and analyze quantitative and qualitative data. The Overall Assessment of the Speaker's Experience with Stuttering (OASES) was administered at three times points: pre-convention, post-convention, and three months following the convention. Semi-structured interviews were conducted with seven participants to further explain the quantitative results.
Results: Analysis of OASES scores across the three time points indicated that there were significant decreases in the negative impact of stuttering between pre-convention and post-convention measures. Qualitative analysis of semi-structured interview transcripts revealed five themes related to community building, collaborative learning, cognitive and communicative changes, self-acceptance, and normalizing stuttering.
Conclusion: SSOs may be beneficial in reducing the negative impact of stuttering and should be considered a potentially valuable addition to traditional therapy for stuttering.

1. Introduction

Coping with stuttering involves more than managing disfluent speech. It includes wrestling with the negative thoughts and emotions, stigma, and social penalties that often accompany stuttering throughout the lifespan (Boyle, Blood, & Blood, 2009; Kalinowski, Stuart, & Armson, 1996; Plexico, Manning, & Levitt, 2009). Because of these challenges, many adults who stutter experience elevated levels of psychological distress (Tran, Blumgart, & Craig, 2011). Presently, there is a rich literature showing that social support is associated with enhanced resilience and reduced distress in many vulnerable groups, including people who stutter

(Blumgart, Tran, & Craig, 2014; Boyle, 2013; Craig, Blumgart, & Tran, 2011; Solberg & Viliarreal, 1997; Thoits, 2011).

Stuttering support organizations (SSOs) are groups that provide people who stutter with support, information, and motivation through mutual assistance (Manning, 2010). The National Stuttering Association (NSA), the National Association of Young People Who Stutter (FRIENDS), and the Stuttering Association for the Young (SAY) are examples of SSOs in the United States. Depending on the organization, SSO events may include monthly support meetings, one-day conferences, or multi-day annual conventions. At SSO events, people who stutter have opportunities to provide and receive unique types of social support from other people with shared experiences or intimate understandings of stuttering. Similar to what has been observed in other vulnerable populations, participating in support organizations is thought to offset some of the distress associated with living with stuttering for adults who stutter (Boyle, 2013; Ramig, 1993; Trichon & Tetnowski, 2011; Yaruss et al., 2002). Currently, the utility of participating in SSOs for children and teenagers who stutter is poorly understood. Here we sought to fill this gap in the knowledge base.

1.1. Key components constituting social support

In the psychology literature, Thoits (2011) describes three types of social support that people with similar experiences can provide to one another. These include emotional sustenance, active coping assistance, and social influence. Because of their direct personal experience, individuals who identify with vulnerable populations can provide emotional sustenance by tolerating expressions of distress, validating feelings and concerns, and providing empathetic understanding. People with similar experiences can also increase each other's capacities to engage in active coping by sharing experience-based information, advice, encouragement, and appraisal feedback. Finally, similar others can provide social influence by serving as role models to one another and inspiring hope for the future (Thoits, 2011).

Trichon and Tetnowski (2011) provided some examples of these types of support in their qualitative study with 12 adults who stutter who participated in a SSO convention. Participants described that, as a result of discussing stuttering openly and building relationships with similar others, the convention provided a unique opportunity to re-define themselves and their relationships with their own stuttering (Trichon & Tetnowski, 2011). Results from quantitative studies provide additional evidence supporting the benefits of SSO participation among adults who stutter (Boyle, 2013, 2015). Compared to adults who stutter without SSO experience, adults who stutter with SSO experience reported lower levels of internalized stigma associated with stuttering and were less likely to rate producing fluent speech as moderately or highly important in interactions with others (Boyle, 2013, 2015).

1.2. The importance of reducing distress in young people who stutter

Young people who stutter (YPWS) are not exempt from encountering the adversities that can accompany living with stuttering. Children who stutter are more likely to be bullied than children who do not stutter (Blood et al., 2011; Davis, Howell, & Cooke, 2002; Hayhow, Cray, & Enderby, 2002; Langevin, Bortnick, Hammer, & Wiebe, 1998). As people who stutter accumulate negative social experiences across the lifespan, their risk for experiencing significantly elevated levels of psychological distress increases (Smith, Iverach, O'Brian, Kefalianos, & Reilly, 2014). Preschoolers and primary school-age children who stutter do not report higher levels of anxiety than their typically fluent peers (Andrews & Harris, 1964; Craig & Hancock, 1996; van der Merwe, Robb, Lewis, & Ormond, 2011; but see Blood, Blood, Maloney, Meyer, & Qualls, 2007 for contrasting evidence). Although the precise timing of the onset of anxiety among people who stutter has not been identified, elevated levels of anxiety are thought to manifest in early adolescence (Blood, Blood, Tellis, & Gabel, 2001, 2007; Davis, Shisca, & Howell, 2007; Gunn et al., 2014; Mulcahy, Hennessey, Beilby, & Byrnes, 2008) and intensify in adulthood (see Smith et al., 2014 for a review). People who stutter with higher levels of social support report lower levels of anxiety and depressive mood states (Blumgart et al., 2014). Thus, participating in and receiving social support from SSO conventions may help to ameliorate existing psychological distress and defuse the risk of accumulating distress during the critical developmental stages of childhood and adolescence among YPWS.

The distress associated with stuttering can be painful and puzzling not only to YPWS, but also to speech-language pathologists. Many speech-language pathologists report that they lack confidence in their abilities to work with people who stutter, particularly treating the cognitive and affective components of stuttering (Cooper & Rustin, 1985; Crichton-Smith, Wright, & Stackhouse, 2003; Kelly et al., 1997). Additionally, because some YPWS are reluctant to acknowledge or discuss their stuttering (Blood, Blood, Tellis, & Gabel, 2003; Hearne, Packman, Onslow, & Quine, 2008), it can be difficult for speech-language pathologists to facilitate meaningful conversations about stuttering in the therapy room. Several authors have acknowledged this challenge and described how to integrate strategies targeting the cognitive and affective components of stuttering into speech therapy (Chmela & Reardon, 2001; Ramig & Dodge, 2010; Reeves & Yaruss, 2012; Reitzes, 2006; Yaruss, Pelczarski, & Quesal, 2010). There is general agreement that addressing negative communication-related thoughts and emotions in stuttering therapy constitutes best practice. While meaningful discussions related to stuttering often occur in the context of therapy, YPWS may still be missing out on the unique benefits of talking about stuttering with other people who stutter. If participating in SSOs provides YPWS with positive outcomes that are similar to those reported by adults, participation in these groups could be a valuable addition to stuttering therapy. Further, for YPWS whose primary concerns relate to their own negative reactions to stuttering, and/or those of their family and friends, peer support through SSO participation may be the preferred and perhaps sole intervention tool.

As a first step in exploring the utility of SSOs in helping YPWS examine or change the internal and external consequences of stuttering, we sought to assess the influence of participating in a SSO convention in this population. In the current study, we used a mixed methods research approach to explore both experiences and outcomes associated with participating in a SSO convention among YPWS. The advantages of using both quantitative and qualitative methods allowed us to obtain a richer understanding of the topic of interest (Johnson, Onwuegbuzie, & Turner, 2007).

The primary purpose of the current study was to investigate if attending a multiday SSO convention was associated with cognitive and affective changes in YPWS. Additionally, we aimed to explore how YPWS make meaning of their experiences with social support at a multiday SSO convention. The quantitative strand, which included repeated measures of the Overall Assessment of the Speaker's Experience with Stuttering (OASES; Yaruss & Quesal, 2010), was used as the primary data source for answering the research questions; the qualitative strand, consisting of data from semi-structured interviews, was used to expand upon and explain the quantitative results.

2. Methods

2.1. Participants

The procedures in the current study were approved by the Institutional Review Board at The University of Iowa. Participants were recruited from the 2016 FRIENDS Annual Convention in Columbus, Ohio. Stuttering status was based on parent report as indicated in the conference registration materials. All attending young people whose parents indicated that they stutter (n = 40) were invited to participate in the study. On the first day of the conference, 31 participants enrolled in the study. Data were collected across three time points (the first day of the convention, the last day of the convention, and three months after the convention). Participants were included in the final sample if they completed the study protocol at each time point. Two participants were excluded because they had to leave the conference early and, thus, did not complete protocol on the last day of the convention. Seven participants were excluded because they did not complete the three-month follow-up protocol.

The final sample included 22 participants (5 females and 17 males) with a mean age of 14.72 years (range = 10–18, SD = 2.27). Twenty participants identified as Caucasian, one as African American, and one as Biracial. On average, participants had attended 3.7 previous FRIENDS Annual Conventions, and five participants were first-time convention attenders. To obtain an estimate of stuttering severity, the participants' parents responded to a Likert scale question ("*How would you rate your child's stuttering behavior?*") at the conference using the following scale: 1 = mild, 2 = mild to moderate, 3 = moderate, 4 = moderate to severe, 5 = severe. Participants who were 18 years old had the option to rate their own stuttering severity. The mean stuttering severity rating was 2.8, which corresponded with a mild-to-moderate rating, and ratings ranged from 1 (mild) to 4 (moderate-to-severe).

2.2. Description of convention

FRIENDS conventions are 2.5 day, volunteer-lead annual events designed to provide YPWS, their families, and speech-language pathologists with support, education, and empowerment. The structure of a typical convention includes an opening ceremony, workshops, semi-structured socializing opportunities, and a final banquet. At the opening ceremony, attendees participate in ice-breaker activities to settle into the environment of the convention and to get to know one another. Throughout the convention, attendees participate in individualized workshops tailored to their unique needs based upon their age and identities. At any given time, multiple workshops are ongoing including workshops designed specifically for people who stutter (children, pre-teen, adolescent, young adult, and adult groups), their parents, siblings, and significant others, and for speech-language pathologists. To develop shared understandings between groups, combined group workshops are also offered (e.g., children who stutter and their siblings, adolescents who stutter and their parents, etc.).

The timing and order of the workshops over the course of the convention are intentionally structured to promote meaningful experiences for attendees. Early-convention workshops are designed to create environments for attendees to develop social connections, share their communication-related experiences, and provide and receive group support. Mid-convention workshops are designed to provide opportunities for attendees to more intentionally examine their views about their own stuttering through discussion and art, music, and movement activities. Late-convention workshops are designed to desensitize and empower attendees by participating in action-oriented experiences. During these workshops, attendees sometimes go on "outings" to increase their communicative comfort outside of the context of the convention. With the support of their families and speech-language pathologists, YPWS set their own goals for the outings (e.g. stuttering openly in public or self-disclosing to a stranger). Open microphone sessions also occur toward the end of the conventions. These sessions provide YPWS with opportunities to engage in public speaking by sharing their thoughts about communication or experiences at the conference with an attentive and supportive audience.

Semi-structured socializing opportunities are embedded between workshops throughout the convention. Attendees eat all meals together at the convention hotel, and evening and late night activities (e.g. bowling, popcorn parties) are offered. The convention concludes with a banquet, which includes dinner, dancing, and karaoke.

YPWS are involved in many aspects of convention planning and execution. At the conventions, YPWS make announcements and introduce speakers. Workshop facilitators and panelists, often adults who stutter and speech-language pathologists, are selected by the FRIENDS executive board. There were a variety of different types of workshops at the 2016 Annual Convention. For example, there was a panel called "Young People Speak" in which YPWS spoke about their experiences with stuttering. Additionally, there were workshops where people who stutter could discuss and practice self-disclosure or participate in a mock interview. Other examples of workshop activities included writing letters to stuttering, stuttering contests, and practicing communication in improvisation games.

Each annual convention follows a theme (i.e. "Looking Back at Where You've Been" or "The Strength of Stories"), which threads together through convention activities throughout the 2.5 days. The theme of the 2016 FRIENDS Annual Convention was "Breaking Down Walls." Readers are encouraged to visit the FRIENDS webpage (https://www.friendswhostutter.org/) for additional

information about the organization and conventions.

2.3. Quantitative data collection and analysis

The Overall Assessment of the Speaker's Experience with Stuttering (OASES; Yaruss & Quesal, 2010) was used as a repeated measure to evaluate the impact of stuttering on the participants' lives at three time points surrounding attendance at the convention; before (pre-convention), immediately after (post-convention), and three months afterwards (follow-up). To determine if cognitive and affective changes were associated with attending the convention and to investigate if potential changes were maintained, participants completed an age-appropriate form of the OASES (i.e. OASES-S, OASES-T, OASES-A) before the convention, on the final day of the convention, and approximately three months after the convention. The three-month follow-up OASES was mailed to participants and returned to investigators in a pre-addressed envelope. The OASES was selected as a repeated measure in the current study because it is a highly consistent measure, with minimal day-to-day variability (Constantino, Leslie, Quesal, & Yaruss, 2016). Additionally, the OASES has been used as a repeated measure in other studies evaluating cognitive and affective changes associated with short-term interventions for YPWS (e.g. Byrd, Hampton, McGill, & Gkalitsiou, 2016).

All forms of the OASES yield an Overall Impact Score as well as individual impact scores for four inter-related sections that characterize the lived experience and impact of stuttering on the individual. Section 1: *General Information* evaluates general knowledge and feelings related to stuttering and communication. Section 2: *Your Reactions to Stuttering* evaluates cognitive, emotional, and physical reactions to stuttering. Section 3: *Communication in Daily Situations* evaluates levels of communication difficulty across contexts. Section 4: *Quality of Life* evaluates how stuttering interferes with various domains of life including education, relationships, and other areas. The number of items in the OASES ranges from 60 in the OASES-S for school-age children to 100 in the OASES-A for adults. Participants rate items on the OASES using a Likert-score ranging from 1 to 5, with 5 being the most severe negative impact. Responses to items within each section are averaged to obtain section-specific impact scores. All completed items are averaged to obtain the Overall Impact Score (Yaruss & Quesal, 2010).

Friedman tests with post hoc analyses were used to determine if there were significant changes in OASES scores between the three time points. Friedman tests, the non-parametric equivalent of repeated measures ANOVA, were appropriate because OASES scores lie on an ordinal scale and were not normally distributed. Cohen's *d* effect sizes were calculated to evaluate the clinical significance of the results.

2.4. Qualitative data collection and analysis

To understand how participants made meaning of their experiences at the FRIENDS convention, semi-structured online video interviews were conducted with a subgroup of participants within a month and a half after the convention. Online video interviews are an increasingly popular tool in qualitative research (Janghorban, Roudsari, & Taghipour, 2014) and have been used in other qualitative studies with people who stutter (e.g., Douglass, Schwab, & Alvarado, 2018). The video conferencing platform Zoom was used to confidentially conduct all interviews. Zoom provides a high level of security, with encryption and individual password protected meeting codes for each participant. It is used university wide as the video conferencing platform of choice at Loma Linda University, the location of the second author.

To reduce the likelihood of the investigator influencing the participants' interview responses, the second author – who did not attend the FRIENDS 2016 convention and who has no previous professional affiliation with FRIENDS – conducted the semi-structured interviews. Participants were selected using a maximum variation sampling strategy; that is, we attempted to capture multiple perspectives of the FRIENDS convention by purposefully recruiting participants with diverse characteristics (Patton, 2002). The final sample consisted of seven participants (four females and three males) who were selected based on variability in their previous experiences with SSOs and in the degree of change in their overall OASES scores from pre- to post-convention. In other words, to maximize diversity within the sample, participants with the least and most previous SSO experience were invited to participate as well as participants who demonstrated positive, negative, and relatively neutral changes in OASES scores from pre- to post-convention. Table 1 contains in-depth descriptions of each participant, with pseudonyms used for confidentiality. Participant recruitment for online interviews ceased when the qualitative data became saturated, or when no new codes emerged during analysis of a new interview transcript.

Table 1
Description of Participants who Completed Interviews (n = 7).

Pseudonym	Age	Gender	Number of previous annual conventions	Pre-conference Overall OASES score	Change in Pre to Post Overall OASES score	Self/Parent-rated Stuttering Severity
Jenna	18	F	2	2.79	−0.75	Moderate
Nicole	14	F	0	2.61	−0.41	Mild-mod
Henry	15	M	0	3.56	−0.78	Moderate
Emily	14	F	3	2.57	−0.54	Moderate
Lucas	18	M	7	1.49	−0.18	Mild
Ian	15	M	5	1.5	0.11	Mild-mod
Alice	12	F	2	2.46	0.11	Mild-mod

*Overall OASES scores range from 1 to 5, with 5 the most severe negative impact. Negative change scores indicate a decrease in the negative impact of stuttering.

To protect privacy, the interviewer was alone with her office door closed during all interviews. Participants were interviewed via Zoom from enclosed rooms within their homes. Six of the seven participants were alone during the interview, and one participant's mother was present for the initial components of the interview. The child whose mother was in the room stated that his answers were not impacted by her presence. Zoom videos were stored on a dedicated external hard drive. The hard drive was stored in a locked drawer in the second author's office when not in use for research purposes.

A topic guide was used to elicit conversation about the participants' experiences at the 2016 FRIENDS convention. The questions on the topic guide included; 1) *Tell me about yourself and your previous experience with FRIENDS*, 2) *Tell me a bit about what the FRIENDS convention was like this summer*, 3) *What specific things did you like about the convention?*, 4) *What specific things did you not like about the convention?*, 5) *Have you changed the way you think or feel about stuttering since the convention? If so, how?*, 6) *If your thoughts and feelings have changed, what part of the convention do you think helped to change them?*, and 7) *Was there anything that was hard or uncomfortable during the convention?* If conversation strayed from the topic guide (but was still related to experiences with the convention), the investigator followed the participants' lead and asked neutral follow-up questions (e.g., "*Can you tell me more about that?*" and "*What do you mean by that?*").

The first and second authors used Braun and Clarke (2006) six phase thematic analysis protocol to analyze the qualitative data. The analysis process was inductive and data-driven, meaning that codes and themes were not bound to the specific questions asked by investigators. In phase one, we added an additional step from Attride-Stirling (2001) to reduce data from the transcripts into meaningful units. This method of data analysis was also used in Gerlach and Subramanian (2016). Table 2 contains descriptions and examples of the six steps involved in the analysis.

Two strategies, including investigator triangulation and member-checking, were used to increase the credibility of the qualitative findings. Investigator triangulation, or including multiple investigators in the data analysis process, enhances validity in qualitative research because it reduces the likelihood that a person's individual biases dictate the development of themes (Denzin, 2007; Mathison, 1988). Additionally, we solicited participant feedback on the themes through a member-checking process to increase the trustworthiness of our interpretations (Ryan-Nicholls & Will, 2009). Specifically, we emailed the participants a summary of the main themes and invited them to provide feedback about the extent that the themes represented their experiences and views. The participants did not request any changes.

Table 2

Description and Examples of Qualitative Data Analysis Protocol.

Step	Description	Example
1	The second author created transcripts of the online interviews. The first and second authors read each transcript at least two times. The second author partitioned the raw data into meaningful units (Attride-Stirling, 2001), or short utterances related to the topic of interest – which was "How did YPWS make meaning of their experience at the 2016 FRIENDS Annual Convention?"	Example of a meaningful unit: *"And I think what I really appreciate about FRIENDS is that it highlights the different levels along the spectrum of acceptance, and it shows that we're all just trying and trying together."*
2	Separately, the first and second authors used the constant comparative method (Glaser & Strauss, 1967) to assign one or more initial codes to each meaningful unit. Codes consisted of single words or phrases that described each segment of raw data.	The first author assigned the following codes to the meaningful unit above: - *positive experience* - *learning from others* - *perspective shift* - *normalized stuttering* - *sense of community* - *vulnerability* In a separate analysis, the second author assigned her own meaningful units, which included: - *helpful* - *positive role models* - *self-acceptance/self-confidence* - *safe environment* - *community*
3	Still working individually, the authors used their coding schemes to collate meaningful units. Then, using axial coding (Glaser & Strauss, 1967), the authors examined relationships within and between codes to identify candidate themes.	Along with other units and codes, the meaningful unit above and its initial codes contributed to the authors developing the following candidate themes: First author: *"Children and teens develop a sense of community and build strong, lasting relationships."* Second author: *"There is value in community and bonding with others who are similar"*
4	The authors met to compare and discuss candidate themes, focusing on reducing overlap between themes and increasing the validity of themes. Candidate themes were discussed, edited, and merged until the authors reached a consensus on the final themes.	The first and second author compared, contrasted, and discussed their individual candidate themes.
5	The authors named and defined the final themes.	The authors agreed upon the following final theme name: *"Children and teenagers built strong relationships and a sense of community in a safe environment."*
6	A report containing descriptions and examples of each theme was developed.	The first and second authors collaborated to define and provide examples of the theme in the manuscript.

3. Results

3.1. Quantitative results

To determine if the distribution of OASES scores differed between the three time points, five omnibus Friedman tests (one for the Overall OASES scores and one for each OASES subsection) were conducted. Results for four of the five OASES measures were statistically significant including the Overall OASES (χ^2(2) = 8.46, p < 0.05), Section 1: *General Information* (χ^2(2) = 6.02, p < 0.05), Section 2: *Reactions to Stuttering* (χ^2(2) = 10.05, p < 0.01), and Section 3: *Communication in Daily Situations* (χ^2(2) = 7.90, p < 0.05). Although OASES Section 4: *Quality of Life* scores decreased from pre-convention to post-convention and the change was maintained at follow-up, the differences were not statistically significant (χ^2(2) = 3.31, p > 0.05).

For the four OASES measures with significant results, post hoc pairwise comparisons with Bonferroni correction were conducted to determine which time points differed. Post hoc analyses of the Overall OASES and Section 1: *General Information* revealed statistically significant differences from pre-convention (Mdn Overall = 2.14, Mdn Section 1 = 2.33) to follow-up (Mdn Overall = 1.88, Mdn Section 1 = 2.09), both p's < .05. There was a significant difference from pre-convention (Mdn = 2.28) to post-convention (Mdn = 2.11) for Section 3: *Communication in Daily Situations*, p < 0.05. For Section 2: *Reactions to Stuttering*, a significant difference from pre-convention (Mdn = 2.27) to post-convention (Mdn = 2.01), p < 0.05, and from pre-convention to follow-up (Mdn = 1.96) emerged, p < 0.05. Friedman tests assess differences in median (rather than mean) values across timepoints, which is why median values are listed in the results here. Fig. 1 displays mean OASES subtest scores for the 22 participants at each time point.

To estimate the clinical significance of the results, Cohen's d effect sizes were calculated for each OASES measure to examine the magnitude of the effects. Cohen (1988) classification criteria were used, with effects greater than 0.2 classified as small, greater than 0.5 classified as medium, and greater than 0.8 classified as large. All statistically significant post hoc results yielded small effect sizes ranging from 0.27 (Section 3: *Communication in Daily Situations* from pre- to post-convention) to 0.49 (Section 2: *Reactions to Stuttering* from pre-convention to follow-up).

To obtain additional information about specific changes within each OASES section, subsequent item-by-item analyses were conducted using descriptive statistics. Because the number and wording of items differ between versions of the OASES, only data obtained from the 15 adolescents (who took the OASES-T) were used in these analyses. The items with the largest changes in average scores across the three time points related to decreased difficulty with talking in a number of contexts (e.g., large groups time pressure situations), increased confidence and knowledge about stuttering, and reduced negative reactions to stuttering (e.g. loss of eye contact). Fig. 2 displays the items with the largest change in mean scores for the OASES sections that changed significantly from 1) pre-convention to post-convention, and 2) pre-convention to follow-up.

3.2. Qualitative results

The second author partitioned the seven semi-structured interview transcripts into one hundred and sixty-three meaningful units (*M* = 26 *SD* = 8.3). Through discussion between the first two authors, sixteen candidate themes were narrowed to five final themes. All seven participants contributed at least one meaningful unit to each theme.
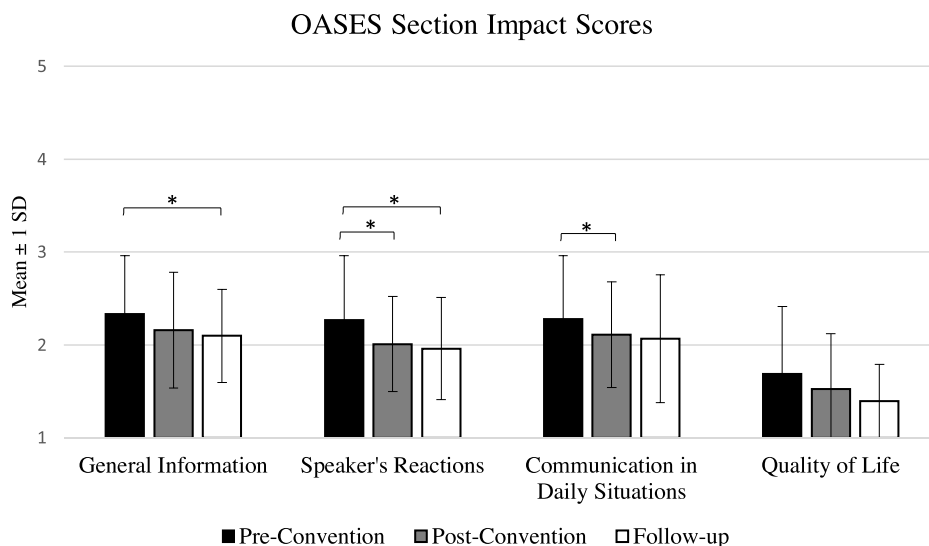

Fig. 1. Group mean ± SD of the OASES Sections for participants at pre, post and follow-up (n = 22).
Notes: * p < 0.05. ± Standard deviation is displayed because standard error bars are not meaningful for within subject comparisons.

Section 3: Communication in Daily Situations
Decreased difficulty with…
   Q42: "talking when you are upset about something or in a hurry" (-0.53)
   Q45: "talking to a large group of people" (-0.53)
   Q52: "talking with people you have just met for the first time" (-0.42)

Section 2: Your Reactions to Stuttering
Stronger disagreement with…
   Q34: "my stuttering keeps me from doing the things I want to do in my
      life." (-0.74)
   Q40: "I do not have confidence in my abilities as a speaker" (-0.58)
Reduced frequency of…
   Q29: "not [saying] what you want to say because you might stutter
      (e.g. change words, not answer questions, order food you don't
      want because it is easier to say)" (-0.53)

Section 1: General Information
Increased knowledge of…
   Q7: "factors that make people stutter more or less often" (-0.6)
Increased frequency of…
   Q5: saying "exactly what you want to say even if you think you
      might stutter" (-0.5)
Increased positivity in feelings about…
   Q11: "being called a person who stutters by other people" (-0.47)

Section 2: Your Reactions to Stuttering
Reduced frequency of…
   Q26: "breaking eye contact/looking away from people when you
      are talking (whether you are stuttering or not)" (-0.73)
   Q31: "letting other people talk for you" (-0.6)
   Q25: "blinking your eyes, making a fist, moving your head, or
      making other movements when you stutter" (-0.53)
   Q29: "not [saying] what you want to say because you might stutter
      (e.g. change words, not answer questions, order food you don't
      want because it is easier to say)" (-0.53)
Stronger disagreement with…
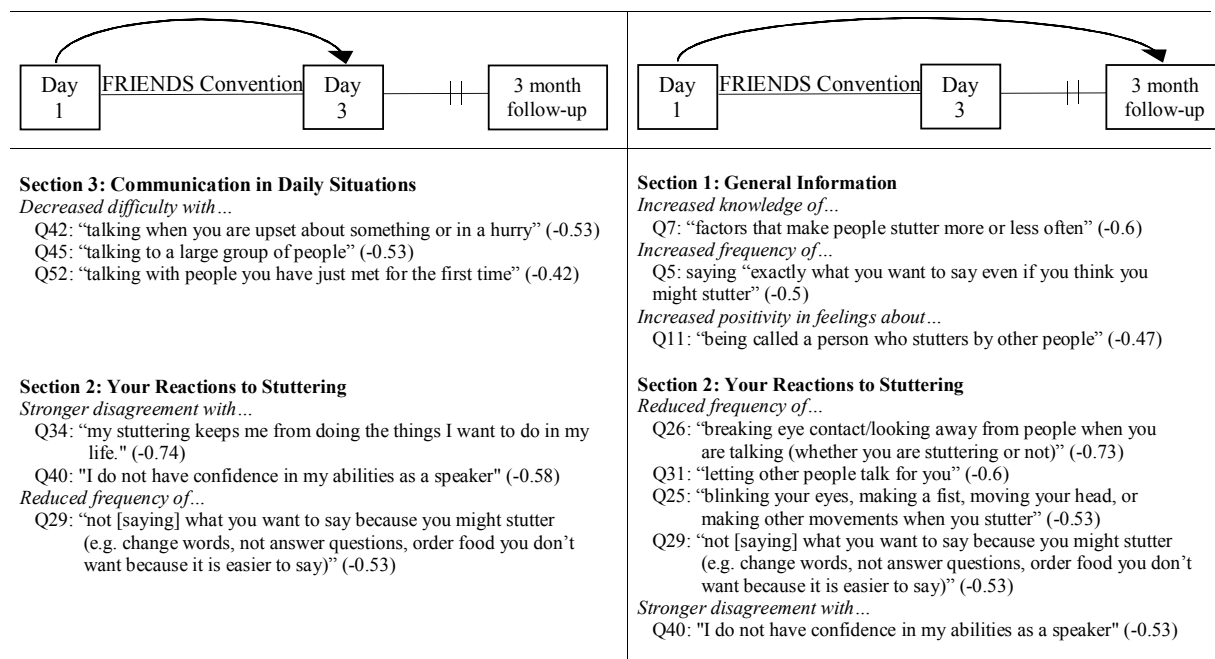   Q40: "I do not have confidence in my abilities as a speaker" (-0.53)

Fig. 2. OASES-T Items with the Largest Change in Mean Scores (n = 15).
Note: The analysis only included data from the 15 adolescent participants. Parentheses indicate the change in mean scores. Items were scored on a 1 to 5 Likert scale, with 1 being the most positive response. Negative values reflect positive cognitive changes.

3.2.1. Theme 1: Children and teenagers built strong relationships and a sense of community in a safe environment

Participants described the benefits of being around other people who stutter and being immersed in an accepting community. For example, Emily said "it's just like always great to go and have time to spend with other people who stutter and you're in a safe environment." Other participants echoed the idea of safety and support. Lucas described the FRIENDS community as a "second family" and said "[kids] aren't afraid to talk and they're not worried about stuttering." Nicole stated the environment "was really understanding, because if you stutter that's okay. I've only been in an environment like that twice, so it was really cool to be in an environment like that."

In addition to facilitating feelings of comfort and community, the participants perceived the FRIENDS convention as a place for developing meaningful friendships through shared experiences. Henry said, "I met a lot of new friends there, too. I liked how there were so many stutterers in one place and we all put our ideas together to make our lives better, I guess you could say." Similarly, Lucas commented "stuttering can bring people together and I notice how much I really love people and kids just embracing their stuttering."

3.2.2. Theme 2: Collaborative learning facilitated personal growth

Participants reported that learning about other peoples' experiences with stuttering helped them better understand their own. After observing other people who stutter "talk a lot" at the convention, Nicole realized "I can talk a lot too even though I stutter." Another participant, Jenna, said, "It's a lot easier to notice on someone else who stutters how little it matters, so I think FRIENDS is really great for that reason."

Younger participants, like Alice, thought opportunities to learn from older teenagers were particularly useful, stating "the teen workshops were helpful where we were like talking to each other … you get to learn about stuff and about stuff about you." On the flip side, older teenagers reported benefits from the opportunities to lead, teach, and mentor. Lucas and Ian described the opportunities as "challenging" and "hard" at the beginning, but "all good" and "super easy" when they were over. Jenna described her experience of accepting a leadership challenge from a FRIENDS coordinator:

> "This year I was asked to make an effort to make sure that new people felt welcome, so one of my responsibilities was to go up to anyone who was there for the first time and start a conversation. That was a little hard cause it's still hard for me to introduce myself, so I was really stepping out of my comfort zone. But it was only really hard at the beginning. But after that it was easier to see that it meant more to them that I went out of my way to talk to them than my stuttering taking away from that moment. So that was a cool change in attitude from the start to the end."

3.2.3. Theme 3: Communicative and cognitive changes persisted beyond the convention

All participants described implementing at least one communicative or cognitive change upon returning home from the FRIENDS convention. Emily described a communicative change related to discussing stuttering openly, stating, "I have started to talk [to] a few

more people about my stuttering." Alice also reported she had started "telling people" about stuttering and raising her hand more often in class.

In addition to communicative changes, participants also discussed cognitive changes regarding their thoughts about communication. Nicole, a first-time FRIENDS convention attender, said, "Since I went to the [convention], I feel more comfortable when I talk about stuttering and when I stutter for the most part. I mean, I still feel nervous but it's not as bad as before." Jenna described an experience that required public speaking that occurred after the convention. She said, "Remembering how well received I was at FRIENDS made me less self-conscious about my stutter. Because I realized if I care about how fluent I sound, then other people will."

3.2.4. *Theme 4: Hearing and sharing personal stories increased self-acceptance and acceptance of others*

Participants discussed the role of hearing personal stories from role models, including peers, volunteers, and speakers, in normalizing stuttering. For example, Ian said, "people telling me about their own ways of dealing with [stuttering] and being confident about it just really resonated with me." Nicole also illustrated the value of personal stories from role models, stating:

> I just liked hearing everyone speak about their stutter because I hadn't really been to anything where a bunch of people just openly talked about the stutter before. So it was probably just hearing everyone making their speeches about their stutter that really impacted me.

Personal stories served as a springboard to increased acceptance of stuttering. For Nicole, it was her own self-acceptance. She said, "Basically hearing the other girls talk like in public places, like at a restaurant and stuff, just taught me to think differently about my stutter and not try to hide it so much and to talk more." For Henry, hearing personal stories increased his acceptance of others and their reactions to his stuttering in everyday interactions. He commented:

> [Hearing stories] helped me learn that you need to be more understanding of people if they say something bad, cause like stuttering isn't like the main thing people would think of. You just need to be more accepting of people when they don't know [about stuttering] and try to teach them."

3.2.5. *Theme 5: Living with stuttering can be hard, but the convention helped normalize stuttering*

Participants described the challenges of living with stuttering. Jenna said, "Sometimes it's hard to believe that I matter as a person who stutters [and that] people are going to want to take the time to listen to me." Emily discussed the specific challenges of self-disclosing when she said, "It's always hard to tell somebody that you stutter. When you meet someone it's always an awkward moment, you don't know how to explain it." However, the participants also described the ways in which participating in the FRIENDS convention alleviated some of the challenges.

Participants reported that attending the convention de-emphasized their perceived needs for fluency, while simultaneously normalizing stuttering. Henry and Lucas said that, prior to the convention, they used to think stuttering was something "bad." Henry elaborated that he used to wish "he could talk like a normal person," but that attending the convention made him "a lot more accepting of [himself]." Emily described learning "[Stuttering] is okay. I don't have to be scared of it or hide it. It's just a part of who you are."

Several of the participants reported that attending the convention helped them to not only accept stuttering, but to view it as something positive, or even as "a gift" (Lucas). Emily said, "they taught us how to explain [stuttering] like a positive thing – like you persevere … and you're a better communicator for it." After listening to the keynote speaker's presentation and talking with him personally about "vulnerability and making the choice to embrace stuttering," Jenna said she was "able to see a way that [stuttering] could act as an asset" for the first time.

4. Discussion

The purpose of the current study was to explore the utility of attending a stuttering support organization convention for young people who stutter. In this mixed methods study, 22 YPWS who attended the FRIENDS 2016 Annual Convention completed the OASES before (pre-convention), immediately after (post-convention), and three-months following the convention (follow-up). In comparison to pre-convention levels, YPWS reported a significant decrease in the negative impact of stuttering on their lives after attending the convention. Analysis of qualitative interviews with 7 YPWS revealed that the convention helped to normalize stuttering and increase self-acceptance by providing a safe place to engage in collaborative learning and build a sense of community. Without a no-treatment control group, conclusions about causality are not definitive; however, the quantitative and qualitative results provide converging, albeit preliminary, evidence that attending an SSO convention resulted in positive cognitive and affective changes that were maintained for at least three months.

4.1. *What specific changes were associated with attending the SSO convention?*

Children and adolescents who attended the FRIENDS 2016 Annual Convention showed the largest changes in their reactions to stuttering, as evidenced by their scores on the OASES. For example, the Section 2: *Reactions to Stuttering* section of the OASES was the only quantitative measure that significantly decreased from the first to the last day of the convention and remained significantly lower at the three-month follow-up. Compared to the other OASES measures, changes in the Section 2: *Reactions to Stuttering* section scores also had the largest effect size, falling just below the moderate range (Cohen's $d = 0.49$) from the first day of the convention to follow-up. The follow-up item-by-item analysis revealed that participants perceived themselves as more confident and more likely to

say exactly what they wanted to say after attending the convention. In the interviews the participants further elaborated on how their reactions to stuttering were becoming less negative. They supplied examples such as discussing stuttering openly and "talking more." This decrease in negative reactivity is important as previous research has shown that "deawfulizing" stuttering and promoting self-acceptance is one of the most powerful influencers of not only the likelihood of an individual participating in the community, but of progress toward speech therapy goals and preventing relapse (e.g., Cooper, 1997; Evesham & Fransella, 1985; Manning, 2010; Yaruss, 1998). SSOs may be a powerful means to help YPWS reframe their thinking.

After attending the SSO convention, there was a significant decrease in the level of participants' perceived difficulty with communication from pre- to post-convention, but the change was not maintained three months after the convention (as measured by OASES Section 3: *Communication in Daily Situations)*. That is, as a group the YPWS perceived that talking became less difficult from the first to the last day of the convention, but only some YPWS continued to perceive talking as less difficult after returning home. Consistent with previous research with adults who stutter, YPWS reported that the "safe" environment of the SSO convention provided them with a space to stutter openly and decreased the perceived importance of producing fluent speech (Boyle, 2015; Trichon & Tetnowski, 2011). Future research should further investigate what elements of SSO conventions make it easier for YPWS to communicate and why only some YPWS report that communication continues to be less difficult after returning home from the convention.

Finally, YPWS showed a significant increase in their knowledge about stuttering and in the general positivity of their feelings toward stuttering after attending the convention. In interviews, participants discussed that attending the convention helped them realize stuttering could be something they could "embrace" and talk openly about, as opposed to something "bad" they should try to hide. Similarly, results from the item-by-item analysis indicate that participants felt more positive about being called a person who stutters by others after the convention. However, these changes (as measured by changes in Section 1: *General Information* OASES scores) were not significantly different from pre-convention levels until three months after the convention. It is possible that for some YPWS, the emotional benefits of attending the convention were not fully realized until they had opportunities to integrate their new perspectives about stuttering into their actions in their day-to-day lives. In interviews, some YPWS reported the emotional changes they made at the convention (e.g. reducing their worries stuttering) increased their participation in activities of daily living when they returned home. One adolescent reported that she joined a drama club after attending the convention, something she "wouldn't have been comfortable enough to do" without her experience at the SSO convention. Other YPWS said they became more likely to raise their hands in class or to discuss their stuttering openly with others after attending the convention.

4.2. Embedding the current findings in a broader framework of social support

SSO conventions provide people who stutter with opportunities to interact and build relationships with other people who stutter. Thoits (2011) asserts that people with shared experiences can provide unique types of support to one another in the forms of active coping assistance, social influence, and emotional sustenance. Next, using the qualitative results, we highlight examples of each of these types of support.

Participants provided examples of both giving and receiving active coping assistance in the forms of sharing experience-based information and advice with one another. Henry described it as "putting [their] ideas together to make [their] lives better." After learning about other ways to live with stuttering from their peers, Emily and Alice described making active attempts to increase their participation in the social world upon returning home from the convention. The participants also provided several examples of the positive effects of social influence. After observing her peers, Nicole reported realizing that stuttering did not have to prevent her from "talking a lot." Other participants reported that their interactions with other YPWS helped them to "think differently" about stuttering. One participant described that he no longer thought of stuttering as something "bad;" others mentioned that they became less inclined to be afraid of or hide their stuttering.

Finally, participants described receiving benefits related to emotional sustenance both at the convention and after the convention. YPWS described the SSO convention environment as "understanding" and described their peers as "a second family." The empathetic understanding that Jenna received at the convention helped her to sustain emotional stability after the convention. She reported that reflecting on her experiences at the convention helped to reduce self-consciousness during an unrelated public speaking event that took place weeks after the convention.

4.3. Clinical implications

The results from the current study provide preliminary evidence that SSO participation could be a valuable addition to speech therapy for YPWS. It is important for speech-language pathologists to be aware of local and national SSO events and to educate their clients about opportunities within the stuttering community. In instances in which speech-language pathologists feel underprepared to treat the cognitive and affective components of stuttering, SSO participation could be particularly useful in helping to meet the holistic needs of YPWS. This does not diminish, however, the need for further graduate and post-graduate training among speech pathologists in treating maladaptive stuttering-related thoughts and feelings.

If it is not feasible for clients to attend an SSO convention, speech-language pathologists can attempt to facilitate some of the benefits of community-based support by helping YPWS develop relationships and talk about stuttering with other people who stutter. For example, speech-language pathologists can arrange group therapy sessions, social outings, or mentoring programs for YPWS who reside in the same schools or school districts. Long distance opportunities could include Skype hang out sessions or pen pal programs with other YPWS. These types of activities may put YPWS in the path of opportunity for giving and receiving the types of social

support outlined by Thoits (2011), which include active coping assistance, emotional sustenance, and social influence. If opportunities to interact with other YPWS are not available, speech pathologists could consider exposing their clients to and discussing written and digital narratives from other people who stutter (e.g., memoirs and documentaries). There is qualitative evidence that bibliotherapy (or reading and discussing a stuttering memoir) is associated with similar positive cognitive and affective shifts among adults who stutter (Gerlach & Subramanian, 2016).

4.4. Limitations and future directions

The results of this study should be considered preliminary in nature due to limiting factors. First, data collection was limited to a singular SSO event and the participant pool was primarily Caucasian. None of the participants indicated that their stuttering severity was "severe," so results may best represent the experiences of Caucasian individuals with mild to moderate stuttering. In addition, the quantitative outcome data we collected were restricted to repeated measures of a single assessment, the OASES. OASES scores have shown to be highly consistent from day-to-day (Constantino et al., 2016) and have been used to assess short-term stuttering interventions (e.g., Byrd et al., 2016 used the OASES to assess change over a five-day period). Future research should ideally include multiple measures to assess cognitive and affective change. Although the results of the study do suggest that those who attended the 2016 FRIENDS convention experienced benefits, the generalization of these results to other SSO events and organization should be cautioned. Structure, topics, participants, and environment are unique to each SSO, and as such, further research investigating specific components that facilitate positive cognitive and affective change is warranted.

Second, the quantitative data of this study demonstrated that not all YPWS benefited equally from attending the SSO event. It is beyond the scope of this paper to investigate this imbalance of impact. It is, however, further evidence of a need for studies that investigate the 'goodness of fit' between client profiles and therapeutic environments. It is also important to consider that the participants may have been at various "stages of change" (Floyd, Zebrowski, & Flamme, 2007; Prochaska & DiClemente, 1983; Prochaska, DiClemente, & Norcross, 1992), and those that benefited the most from the convention were ready for action. According to the Transtheoretical Model of change, a client is able to make use of the interventions implemented based upon where they are along the continuum of change. It could be that many of the participants who attended the FRIENDS convention were there because they were ready to actively implement change and had the social and cognitive support to facilitate this change.

Finally, past speech therapy experiences, concurrent enrollment in therapy, previous experience with support organizations, and stuttering severity were not controlled for in this study and should be taken into consideration in future studies. It is possible that these factors moderate the extent that participation in SSO events is associated with cognitive and affective change.

5. Conclusion

Many people who stutter are stigmatized throughout the lifespan, beginning with mocking and teasing as early as the preschool years. As people who stutter accumulate stigmatized social experiences, they become vulnerable to experiencing elevated levels of psychological distress. Results from the current study provide preliminary evidence that, similar to adults, YPWS experience cognitive and affective benefits associated with participating in a SSO convention. Although more research is needed, participating in SSO conventions in childhood and adolescence may help to reduce the challenges that can accompany living with stuttering.

Funding

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