

Research Article

Outcomes Following Participation in a Support-Based Summer Camp for Children Who Stutter

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Purpose: Self-help and support activities are often recommended for people who stutter, and there is growing interest in understanding whether and how such experiences might be beneficial for children who stutter. The purpose of this study was to explore the potential impact of participation in Camp SAY, an overnight support-based summer camp experience for children who stutter, by measuring changes in scores on the Overall Assessment of the Speaker's Experience of Stuttering (OASES).

Method: Participants were 107 children who stutter (age range: 8–18 years) who attended Camp SAY during the summers of 2013, 2015, and/or 2016. We examined changes in OASES scores (a) pre- to postcamp, (b) the durability of changes 6 months after the conclusion of the camp, and group differences (c) between school-age campers and teenage campers and (d) between first-time campers and those who had previously attended the camp.

Results: Comparison of precamp to postcamp scores revealed significant improvements related to reactions to stuttering, quality of life, and overall adverse impact of stuttering. Scores on each subsection of the OASES were maintained (and further improved) 6 months after camp. There were no significant differences between school-age campers and teenage campers. Both first-time and returning campers showed significant improvements related to reactions to stuttering, though first-time campers had a significantly larger improvement in attitudes toward communication related to stuttering than returning campers.

Conclusion: These outcomes suggest that participation in support activities, like Camp SAY, is associated with significant reductions in the overall adverse impact of stuttering and can therefore be beneficial for children who stutter.

Group-based support, including participation in self-help organizations and camps, has been shown to be a valuable experience for both children and adults who stutter (Byrd, Chmela, et al., 2016; Byrd, Hampton, et al., 2016; Byrd et al., 2018; Gerlach et al., 2019; McClure & Yaruss, 2003; Trichon et al., 2006; Trichon & Tetnowski, 2011, 2015; Yaruss et al., 2002). Support groups are typically defined as professionally led meetings of people who all have similar issues (Borkman, 1999). Support groups can also be understood as communities of people who have shared experiences who get together to gain moral support and remember that they are not alone in facing their challenges.

Support is frequently recommended as an adjunct to traditional speech therapy to help address the cognitive and affective components of stuttering. Speech-language pathologists (SLPs), particularly those who specialize in stuttering, often encourage clients to attend support groups (Yaruss et al., 2007), and many attend stuttering support group events themselves. Also, many graduate textbooks highlight the importance of stuttering support groups. For example, Manning and Dillolo (2018) wrote, “There is probably nothing as effective as a good support group for increasing people’s ability to communicate” (p. 525), and Guitar (2019) stated, “Support or self-help groups... provide an atmosphere in which members can freely share their feelings and develop a sense of connectedness to others who stutter” (p. 356). Still, there is limited empirical evidence supporting the effectiveness of stuttering support groups, with a particularly limited body of evidence regarding the impact of support programs on children who stutter. Because many clinicians advocate for therapy models

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that emphasize attitudes and emotions in addition to traditional behavioral strategies for managing stuttering (Murphy et al., 2007a; Plexico et al., 2005; Yaruss et al., 2012), it is important for clinicians and researchers to understand whether or how support groups may be beneficial for individuals of all ages who stutter.

Participation in Self-Help/Support Activities by Adults Who Stutter

The studies that have examined stuttering support participation have shown an overall positive effect for adults who stutter (Boyle, 2013; Hunt, 1987; McClure & Yaruss, 2003; Tichenor & Yaruss, 2019; Trichon et al., 2006; Trichon & Tetnowski, 2011, 2015; Yaruss et al., 2002). In one of the earlier studies on stuttering support group participation, Yaruss et al. (2002) examined the experiences of 71 attendees of the National Stuttering Association's 1999 annual conference. Of the study participants, 56.7% reported benefiting from meeting other individuals who stutter, and 93.9% felt that participation in a stuttering support group had a positive effect on their self-image and acceptance as a person who stutters. It is perhaps not surprising that individuals attending a self-help group conference would be more inclined to report positive benefits, given the potential for self-selection bias. Still, findings from this early study shed light on the specific nature of the benefits that participants experience.

Boyle (2013) surveyed 279 adults who stutter—175 with prior support group experience and 104 with no prior support group experience—to examine the potential value of support groups. Of the adults who had experience with stuttering support groups, 74.1% reported that participation was helpful. Overall, people with support group experience reported higher values on assessments measuring self-esteem, self-efficacy, and life satisfaction. Likewise, Tichenor and Yaruss (2019) surveyed 502 adults who stutter and found that participation in stuttering support groups was associated with lower adverse impact related to stuttering. Additionally, the adults who reported no prior participation in stuttering support groups were significantly more likely to exhibit negative cognitive-affective reactions to stuttering, such as feeling embarrassed and ashamed, and feeling less empowered in coping with their stuttering.

Qualitative studies (Trichon et al., 2006; Trichon & Tetnowski, 2011) have also shown that attending stuttering support conferences can help to minimize adverse cognitive beliefs about stuttering and reduce the overall adverse impact of stuttering. For example, Trichon and Tetnowski (2011) interviewed 12 adults who stutter 12–18 months after they had attended the National Stuttering Association's 2007 annual conference. Interpretive phenomenological analysis revealed common themes reflecting the benefits of attending the conference, such as socializing with other people who stutter, belonging to a community, and altering cognitive beliefs.

Results from all of these studies yield a consensus that support activities are valuable for adults who stutter.

Meeting other people who stutter, sharing experiential knowledge with peers, gaining moral support, and seeing that one is not alone in facing stuttering are all beneficial outcomes of self-help for adults who stutter. In general, participation in support activities is associated with reduced adverse life impact and more positive cognitive-affective reactions to stuttering.

Participation in Support Activities by Children Who Stutter

Although the benefits of support for adults who stutter are clear, the potential impact of support activities for *children* who stutter is still emerging. Like adults, children who stutter may develop adverse reactions to stuttering, with research showing that awareness, negative perceptions, and concerns about stuttering may emerge as early as 3 years of age (Ezrati-Vinacour et al., 2001; Langevin et al., 2009; Vanryckeghem et al., 2005). Other experiences, such as bullying and negative reactions by others, can also cause adverse consequences for children who stutter (Blood et al., 2011; Blood & Blood, 2016; Langevin et al., 1998; Murphy et al., 2007b). Although researchers and clinicians often refer children who stutter to support groups, more information is needed about the value of support group participation for this age group.

To better understand the impact of support group activities for children who stutter, Gerlach et al. (2019) conducted a mixed-methods study evaluating a 3-day stuttering support convention. Quantitative and qualitative data were collected before, immediately after, and 3 months after the 2016 Annual Convention of Friends: The National Association of Young People Who Stutter. Twenty-two young people who stutter (ages 10–18 years) participated in the study. From preconvention to postconvention, significant changes were observed on two subtests of the Overall Assessment of the Speaker's Experience of Stuttering (OASES; Yaruss & Quesal, 2006, 2016), suggesting a reduction of negative reactions to stuttering and a reduction in difficulty with communication. When stuttering impact was measured 3 months after the convention, participants continued to demonstrate a significant reduction in negative reactions to stuttering compared with before the conference. Additionally, from preconvention to 3 months postconvention, participants reported a significant increase in general stuttering knowledge. Qualitative analyses examining the nature of the changes that participants experienced included a greater sense of community, personal growth, self-acceptance, normalization of stuttering, and improvement in thoughts about stuttering. After attending the support group convention, participants shared sentiments such as "Friends made me less self-conscious about my stutter," and "It's okay to stutter. I can be just as successful and happy as someone who is fluent" (Gerlach et al., 2017). While no significant changes were observed in the OASES quality of life subscore, group means decreased with each time point, suggesting that further exploration of changes in quality of life with larger sample sizes is warranted.

Another example of support activities for children who stutter can be seen in summer camp programs. In recent years, several summer camp programs have emerged for children who stutter. These camps have many commonalities, though they still have diverse underlying philosophies, durations, and treatment models (Byrd, Chmela, et al., 2016; Byrd, Hampton, et al., 2016; Byrd et al., 2018). Many university programs, for example, include elements of intensive group therapy as part of the summer camp experience. For example, Camp Dream. Speak. Live. is “an intensive treatment program” (Byrd, Hampton, et al., 2016, p. 2) with targeted activities and goals related to communication, resiliency, leadership, understanding bullying, and desensitization (Byrd et al., 2018). For Camp Dream. Speak. Live. “The treatment protocol...includes a variety of distinct opportunities designed to address these components [such as] speaking in front of all participants of the program at least two times per day” (Byrd, Hampton, et al., 2016, p. 5). Preliminary outcome data from Camp Dream. Speak. Live. showed that first-time participation in the 5-day summer therapy camp was significantly associated with reduced adverse impact of stuttering, reduced negative reactions to stuttering, improved daily communication, and improved quality of life (Byrd et al., 2018), as measured by the OASES. When not exclusively looking at first-time attendees, Camp Dream. Speak. Live. was associated with significantly improved quality of life (Byrd, Hampton, et al., 2016), again as measured by the OASES. Similarly, participation in Camp Shout Out, a week-long “treatment and training program [that] executes evidence-based therapeutic activities” for children who stutter, yielded a statistically significant difference in the OASES quality of life scores (Byrd, Chmela, et al., 2016).

Despite the fact that there may be differences between formal support groups (Gerlach et al., 2019) and summer camp therapy programs (Byrd, Chmela, et al., 2016; Byrd, Hampton, et al., 2016; Byrd et al., 2018), each of these types of programs includes a significant component of support as defined by Borkman (1999). Both types of programs allow children who stutter to meet others who stutter and to see they are not alone in facing stuttering. Both types of programs also provide a safe space to stutter openly, thereby allowing participants to become desensitized to stuttering. Still, further information is needed in order to better understand the nature of the changes that children may experience through summer camp programs and the specific aspects of these experiences that may be associated with observed changes in the impact of stuttering on their lives.

This Study

In this study, we sought to examine the potential benefits associated with a specific summer camp program for children who stutter. Camp SAY is a 2-week overnight camp for children who stutter and their young family members and friends. The camp is associated with The SAY: The Stuttering Association for the Young, a “non-profit organization that empowers, educates, and supports

young people who stutter,” by providing children (ages 8–18 years) a place where “every young person who stutters has a voice that matters and deserves to be heard” (Camp SAY, 2018; SAY: The Stuttering Association for the Young, 2018). Camp SAY is modeled on a typical summer camp experience, with activities such as theater, swimming, arts and crafts, horseback riding, and sports. In addition, Camp SAY follows the tenets of stuttering support by providing campers with an immersive experience in which stuttering becomes the norm for speaking and communicating. Children meet others who stutter, share lived experiences, and stutter openly, all while gaining desensitization to their stuttering. In all activities (even those not specifically related to speech), campers are immersed within an encouraging, “stuttering friendly” atmosphere; other children, staff, and volunteers who stutter constantly provide campers with positive reinforcement for the development of self-esteem and self-confidence, for speaking freely regardless of whether or not they might stutter, and for saying what they want to say (Gielen & Alden, 2019). Staff are trained in active listening, and children are repeatedly shown that they have as much time as they need to speak. Camp SAY staff are also trained to not interrupt others who are speaking and to emphasize *what* is being said rather than *how* it is said, with no emphasis on fluent versus disfluent speech.

Note that although Camp SAY is distinct from typical summer camps that do not have this focus on stuttering, it is also not a formal therapy program. Camp SAY does not explicitly incorporate any specific therapy goals focused on changing speech fluency or modifying stuttering. Rather, as a support program, Camp SAY programming centers around social interaction with people who stutter as a means of achieving positive change for the participants. Campers do have the opportunity to meet individually with an SLP on staff for expert-level support once or twice during the 2 weeks of camp. SLPs at Camp SAY also provide training for staff and facilitate group conversations, but they do not otherwise provide any systematic or individualized program of therapeutic intervention or training in speech modification or related techniques. This is consistent with the Camp SAY philosophy, which suggests that the vital component for facilitating change is simply being with other people who stutter and receiving support from the community.

Although preliminary evidence shows that summer camp programs and support activities are beneficial for children who stutter, the impact of a summer camp program *that focuses primarily on support* remains unclear. Therefore, this study assesses the potential benefits of Camp SAY. Specifically, this study examined four aims:

1. to assess changes in adverse impact of stuttering that occur following participation at Camp SAY;
2. to compare changes in adverse impact associated with stuttering seen in school-age campers versus that seen in teenage campers after 2 weeks at camp;
3. to compare changes in adverse impact seen in first-time campers versus returning campers after 2 weeks at camp; and

4. to assess the durability of any changes 6 months after the conclusion of camp.

Method

Participants

Data for this study, which were collected over 3 years at Camp SAY (2013, 2015, and 2016), are summarized in Table 1. (Data collection was not attempted in 2014 due to staff transitions and administrative decisions.) Data from 109 unique participants were originally collected across years with no repeat participants. Two outliers (Subjects 21 and 38) were excluded from the data analysis due to consistent scores that were more than 3 *SDs* away from the mean. Thus, a total of 107 unique participants ($n = 20$ females, $n = 87$ males), ranging from 8 to 17 years of age, completed the OASES (Yaruss & Quesal, 2016) forms both precamp and postcamp. Data from these 107 participants were used to evaluate the first three aims: (1) changes in the adverse impact of stuttering over 2 weeks at camp, (2) differences in changes for school-age campers versus teenage campers, and (3) differences in changes for first-time campers versus returning campers. To compare changes seen in school-age campers versus teenage campers (Aim 2), the 107 participants were divided into two groups: school-age campers ages 8–12 years ($n = 39$) and teenage campers ages 13–18 years ($n = 68$). To compare changes seen in first-time campers versus returning campers (Aim 3), the 107 participants were divided into two groups: first-time campers ($n = 43$) and returning campers ($n = 64$).

To assess whether any changes experienced during camp persisted after the completion of camp (Aim 4), a subset of 43 campers of the 107 participants ($n = 12$ females, $n = 31$ males; $n = 10$ school-age campers, $n = 33$ teenage campers) completed the OASES before and after camp, as well as 6 months after attending camp to collect longitudinal follow-up data. Follow-up data were collected in 2016 and therefore included the 47 individuals who attended camp in summer 2016. Four participants could not be reached 6 months after camp despite repeated follow-up e-mails and phone calls. Therefore, the follow-up analysis included the 43 remaining participants from the summer 2016 camp.

Outcome Measure

As noted, the adverse impact of stuttering was measured via school-age and teenage versions of the OASES, a standardized assessment that is routinely used around the world for documenting the impact of stuttering on people's lives. The OASES is divided into four sections: General Information, Speaker's Reactions, Daily Communication, and Quality of Life. The General Information section assesses how much respondents know about stuttering in general and about their speech in particular. The Reactions to Stuttering section assesses how respondents think and feel about their own stuttering, and if secondary characteristics, physical tension, and avoidance behaviors are present. The Communication in Daily Situations section assesses the difficulty people have when communicating in different settings, such as at school, at home, and in social situations. Lastly, the Quality of Life section assesses how much stuttering negatively interferes with respondents' quality of life, based on factors such as the ability to make friends, to succeed in school, and to get a job, as well as their overall confidence in themselves. The OASES was chosen as the outcome measurement because it is a reliable instrument for measuring the adverse impact of stuttering. The school-age and teenage versions of the OASES consist of 60 and 80 questions, respectively. All questions are answered using 5-point Likert scales, with higher scores indicating a greater adverse impact from stuttering. Each section of the OASES can be scored and interpreted individually; the overall score reflects impact across all items in the test.

Data Collection

At the time of data collection, the second author was a full-time SLP at the camp and helped collect the OASES data. Data were analyzed retrospectively, having been previously collected as part of an established Camp SAY protocol for internal quality improvement and marketing purposes. Written parent consent was given upon camp enrollment, and verbal child assent was obtained during data collection. All data were de-identified by this study's second author, and no identifying information was shared with the other authors. The Michigan State University Human

Table 1. Participants within each aim.

Aim	No. of participants by group	Total no. of participants
Aim 1: Assess change of adverse impact after 2 weeks at Camp SAY.	2013 campers: 24 2015 campers: 36 2016 campers: 47	107
Aim 2: Compare change of adverse impact seen in school-age campers versus teenage campers after 2 weeks at Camp SAY.	School-age campers: 39 Teenage campers: 68	107
Aim 3: Compare change of adverse impact seen in first-time campers versus returning campers after 2 weeks at Camp SAY.	First-time campers: 43 Returning campers: 64	107
Aim 4: Assess durability of change 6 months after Camp SAY.	2016 campers with follow-up data	43

Note. SAY = Stuttering Association for the Young.

Research Protection Program/Institutional Review Board (IRB) accordingly determined that the analyses did not involve human subjects and IRB review was not needed.

The OASES was completed by all 107 participants during their first full day of camp (pre) and on their last full day of camp (post). To ensure the quality of the responses, each camper completed the OASES one-on-one or in a small group, with the assistance of a certified SLP or SAY staff member who had been trained to administer the OASES. Depending on the child's age, reading level, and maturity, staff helped the campers read questions and correctly mark their responses, consistent with the instructions provided in the OASES manual (Yaruss & Quesal, 2016). To ensure validity of the participant responses and to avoid examiner bias, examiners were trained to maintain a neutral expression, only respond to the participants using neutral language such as "okay," and not ask follow-up questions. During the summers of 2013 and 2015, all precamp data were collected as soon as the campers arrived at camp. During the summer of 2016, an attempt was made to collect precamp data for 45 campers *before* they arrived at camp, either via the phone or online through a secure videoconference. Campers who could not be reached in the month before camp ($n = 34$) completed the OASES as soon as they arrived at camp. Follow-up data were collected face-to-face (for campers who lived close to SAY's main office in New York City), on the phone, or online through a secure videoconference by the second author (a certified SLP) or by a SAY staff member who was trained to administer the OASES.

Data Analysis

Nonparametric tests were implemented due to lack of normality (Aim 4) and due to significant outliers (Aims 1–4). Therefore, statistical analyses were based on Wilcoxon signed-ranks (Aim 1 pre/post analyses; Aims 2 and 3 within-group differences), Mann–Whitney U (Aims 2 and 3), and Friedman (Aim 4) tests. Because nonparametric analyses were used, effect size was calculated using the formula $r = Z/\sqrt{N}$ (Rosenthal, 1994). Guidelines for r state that a small effect is .1, a medium effect is .3, and a large effect is .5 (Cohen, 1988). The observed outliers shown on the box and whisker graphs were all fewer than 3 SDs away from the mean and were therefore not removed from the data set. An individual α level of .05 was assigned for each subtest of the OASES and the overall impact score. Due to the preliminary nature of this retrospective study, a correction for multiple comparisons was not applied.

Results

Aim 1: Assess Changes in Adverse Impact of Stuttering as a Result of Participation in Camp SAY

Wilcoxon signed-ranks comparisons of OASES scores precamp versus postcamp revealed significant differences on

the Reactions to Stuttering section, on the Quality of Life section, and for the overall score of the OASES. Table 2 reports the median values for each OASES section, as well as the p values comparing precamp and postcamp median scores. As illustrated in Figure 1, after 2 weeks at camp, campers demonstrated a significant reduction in negative reactions to stuttering ($z = -4.44, p < .001$), with a medium effect size ($r = .30$); a significant reduction in the impact of stuttering on quality of life ($z = -2.30, p = .021$), with a small effect size ($r = .16$); and a significant reduction in the overall adverse impact of stuttering ($z = -3.67, p < .001$), with a small-to-medium effect size ($r = .25$). No significant changes were observed in the General Information section ($z = -1.25, p = .213$) or the Daily Communication section ($z = -1.85, p = .065$).

Aim 2: Compare Change of Adverse Impact Seen in School-Age Campers Versus Teenage Campers After 2 Weeks at Camp SAY

Mann–Whitney U tests were used to determine if there were group differences between school-age (ages 8–12 years) and teenage (ages 13–18 years) campers. Table 3 reports the median values for each OASES section for both school-age campers and teenage campers, as well as the p values comparing precamp and postcamp medians within each age group and between age groups. No statistically significant between-groups differences were observed. Test statistics ranged from -0.20 to 1.22 , and p values ranged from .22 to .92. Wilcoxon signed-ranks tests were then applied to assess within-group differences for both school-age and teenage campers. For school-age campers, statistically significant changes were observed in the Reactions to Stuttering section, in the Quality of Life section, and for the overall score of the OASES. As illustrated in Figure 2, after 2 weeks at camp, school-age campers demonstrated a significant reduction in negative reactions to stuttering ($z = -2.10, p = .036$), with a small-to-medium effect size ($r = .24$); a significant reduction in the impact of stuttering on quality of life scores ($z = -2.06, p = .040$), with a small-to-medium effect size ($r = .23$); and a significant reduction in the overall adverse impact of stuttering ($z = -2.51, p = .012$), with a medium effect size ($r = .28$). No significant changes were observed in the General Information section ($z = -0.84, p = .402$) or the Daily Communication section ($z = -1.23, p = .220$). For teenage campers, a statistically significant change was observed in the Reaction to Stuttering section and for the overall score of the OASES. As illustrated in Figure 3, teenage campers exhibited a significant reduction in negative reactions to stuttering ($z = -4.093, p < .001$), with a medium effect size ($r = .35$), and a significant reduction in the overall adverse impact of stuttering ($z = -2.677, p = .007$), with a small-to-medium effect size ($r = .23$). No significant changes were observed in the General Information section ($z = -0.98, p = .328$), the Daily Communication section ($z = -1.37, p = .170$), or the Quality of Life section ($z = -1.26, p = .207$).

Table 2. Aim 1 descriptive statistics and *p* values.

Variable	General information	Reaction to stuttering	Communication	Quality of life	Mean impact score (overall)
Precamp median	2.47	2.30	2.13	1.58	2.16
Postcamp median	2.47	2.00	2.07	1.44	2.02
<i>p</i> value	.213	< .001	.065	.021	< .001

Note. The bolded values indicate significant effects.

Aim 3: Compare Changes Observed in First-Time Campers Versus Returning Campers Following Participation in Camp SAY

Mann–Whitney *U* tests were used to determine if there were group differences between first-time and returning campers. Table 4 reports the median values for each OASES section for both first-time campers and returning campers, as well as the *p* values comparing precamp and postcamp medians within and between groups. A significant change was detected in the Communication in Daily Situations section ($U = 1.691, z = 2.00, p = .045$), with a small effect size ($r = .14$). First-time campers had a significantly larger reduction in adverse communication attitudes compared with returning campers. Specifically, first-time campers saw a median reduction of their Section 2 OASES score of 0.13, suggesting the participants experienced less adverse reactions compared with returning campers, who had no median score

reduction ($Mdn = 0.00$). No other significant differences between groups were observed. For Sections 1, 2, and 4, and overall adverse impact, test statistics ranged from 0.28 to 1.72, and *p* values ranged from .086 to .777.

Wilcoxon signed-ranks tests were then applied to assess within-group differences for both first-time and returning campers. For first-time campers, statistically significant changes were observed in the Reactions to Stuttering section, in the Communication in Daily Situations section, and for the overall score of the OASES. As illustrated in Figure 4, after 2 weeks at camp, first-time campers demonstrated a significant reduction in negative reactions to stuttering ($z = -2.73, p = .006$) with a medium effect size ($r = .29$); a significant reduction of adverse communication attitudes ($z = -2.78, p = .005$), with a medium effect size ($r = .30$); and a significant reduction in the overall adverse impact of stuttering ($z = -3.19, p = .001$), with a medium effect size ($r = .34$). No significant changes were observed in the General Information

Figure 1. Distribution of all participants' pre and post OASES subtest scores and overall impact scores. Each box and whisker plot shows the interquartile range (box) with the median (horizontal bar). The whiskers (vertical lines) extend 1.5 interquartile ranges above and below the upper and lower quartiles, respectively. The outliers (circular dots) are greater than 1.5 interquartile ranges above or below the interquartile range. * $p < .05$, ** $p < .01$ (significance level for five pairwise comparisons with overall $\alpha = .05$).

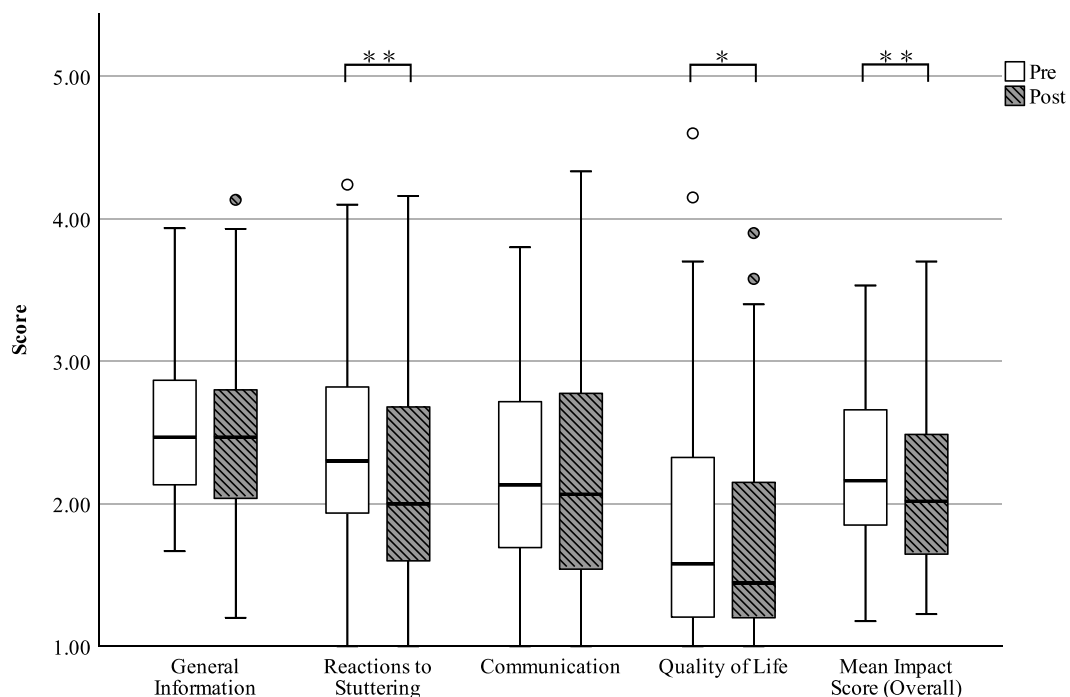


Table 3. Aim 2 descriptive statistics and *p* values.

Variable	School-age campers Teen campers									
	General information		Reactions to stuttering		Communication		Quality of life		Mean impact score (overall)	
Precamp median	2.47	2.47	2.35	2.24	2.15	2.10	1.50	1.64	2.22	2.12
Postcamp median	2.47	2.47	2.05	2.00	2.00	2.18	1.44	1.53	2.05	1.99
<i>p</i> value within group	.402	.328	.036	< .001	.220	.171	.040	.207	.012	.007
<i>p</i> value between groups	.741		.838		.920		.220		.441	

Note. The bolded values indicate significant effects.

section ($z = -1.03, p = .304$) or the Quality of Life section ($z = -1.77, p = .077$). For returning campers, statistically significant changes were observed in the Reaction to Stuttering section (Section 2) of the OASES and for the overall score of the OASES. As illustrated in Figure 5, returning campers exhibited a significant reduction in negative reactions to stuttering ($z = -3.56, p < .001$), with a small effect size ($r = .13$), and a significant reduction of the overall adverse impact of stuttering ($z = -2.05, p = .041$), with a small effect size ($r = .18$). No significant changes were observed in the General Information section ($z = 0.87, p = .386$), the Daily Communication section ($z = -0.10, p = .923$), or the Quality of Life section ($z = -1.48, p = .138$).

Aim 4: Assess the Durability of Changes 6 Months Following Participation in Camp SAY

Friedman tests were used to determine if observed changes in OASES scores were maintained 6 months postcamp. Table 5 reports the median values for each OASES section, as well as the *p* values across time. No statistically significant changes were observed in the General Information section, the Reactions to Stuttering section, and the Communication section of the OASES. Test statistics ranged from 3.25 to 5.18, and *p* values ranged from .075 to .197. Therefore, OASES scores were judged to be durable for 6 months after attending camp. As shown in Figure 6,

Figure 2. Distribution of school-age campers' pre and post OASES subtest scores and overall impact scores. Each box and whisker plot shows the interquartile range (box) with the median (horizontal bar). The whiskers (vertical lines) extend 1.5 interquartile ranges above and below the upper and lower quartiles, respectively. The outliers (circular dots) are greater than 1.5 interquartile ranges above or below the interquartile range. The extreme outlier (asterisk) is greater than three interquartile ranges above the interquartile range. * $p < .05$, ** $p < .01$ (significance level for five pairwise comparisons with overall $\alpha = .05$).

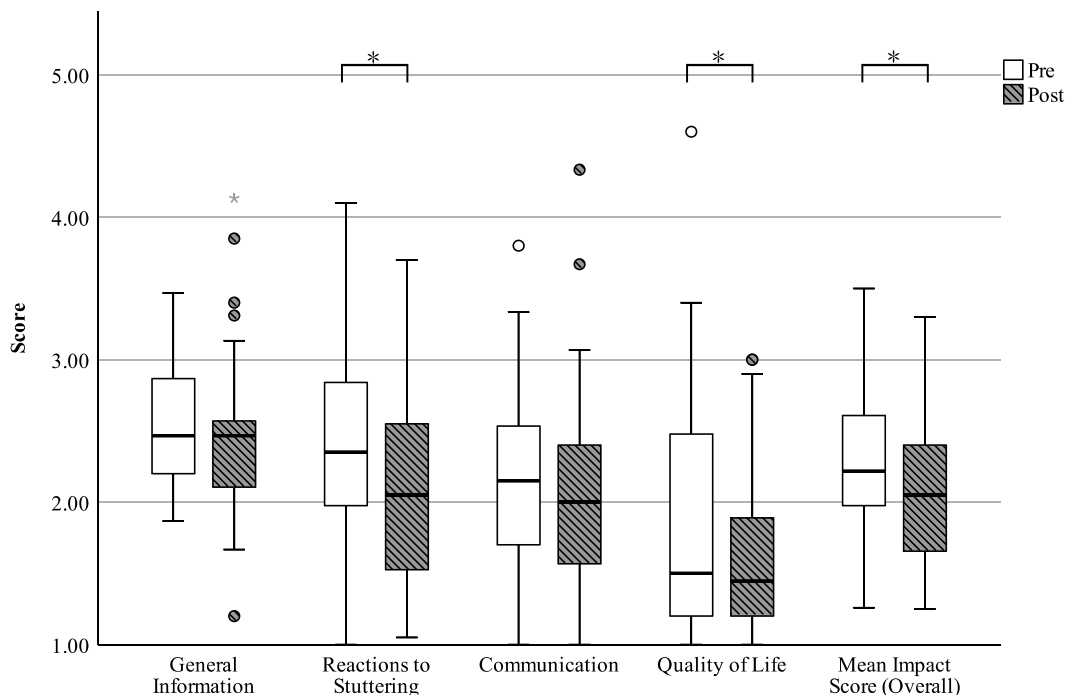
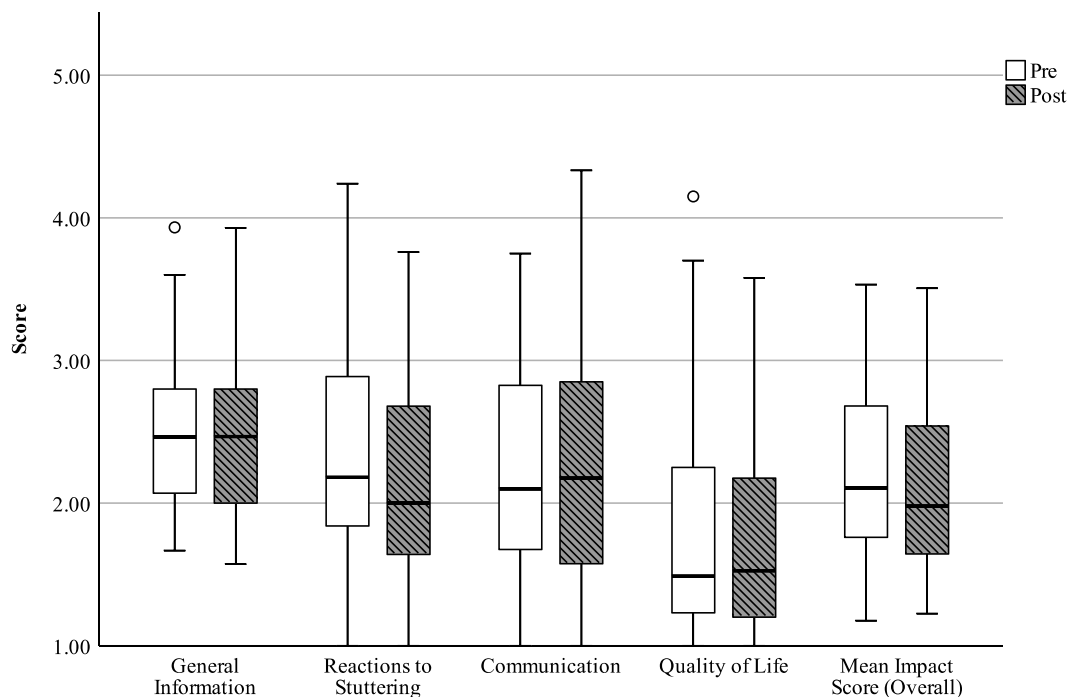


Figure 3. Distribution of teenage campers' pre and post OASES subtest scores and overall impact scores. Each box and whisker plot shows the interquartile range (box) with the median (horizontal bar). The whiskers (vertical lines) extend 1.5 interquartile ranges above and below the upper and lower quartiles, respectively. The outliers (circular dots) are greater than 1.5 interquartile ranges above or below the interquartile range.



the median OASES scores in all subsections actually decreased from precamp to follow-up, potentially signifying an ongoing (nonsignificant) reduction in the negative consequences of stuttering. Significant changes were observed for the Quality of Life section, $\chi^2(2) = 7.69, p = .021$, and the overall OASES score, $\chi^2(2) = 10.33, p = .006$. Post hoc pairwise comparisons revealed a statistically significant reduction of the adverse impact of stuttering on quality of life scores from precamp (*Mdn* score = 1.70) to a 6-month follow-up (*Mdn* score = 1.45), $\chi^2(2) = 7.693, p = .039$, with a small-to-medium effect size ($r = .27$). This difference led to a reduction in overall adverse impact of stuttering from precamp (*Mdn* score = 2.13) to a 6-month follow-up (*Mdn* score = 1.92), $\chi^2(2) = 10.333, p = .006$, with a medium effect size ($r = .34$). Therefore, overall OASES scores were

not only maintained 6 months postcamp; there was also a significant reduction of the adverse impact of stuttering pre-camp to follow-up.

Discussion

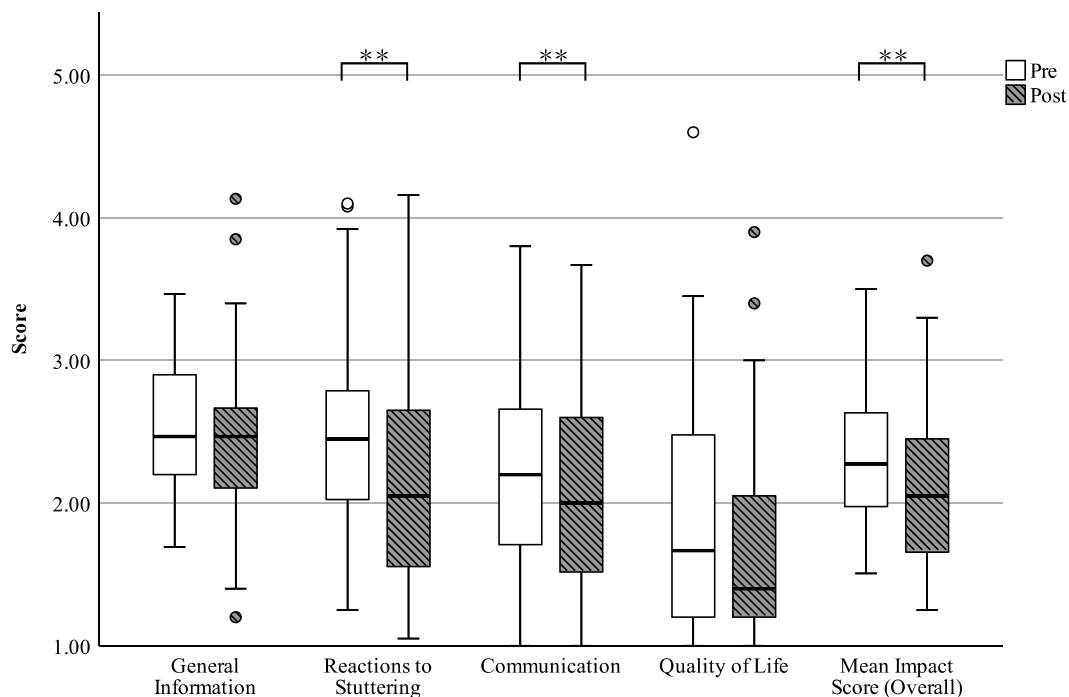
This study sought to examine the potential benefits of a support-based summer camp for children who stutter. For Aim 1, we found that after participating in Camp SAY, children exhibited a significant reduction in OASES scores related to negative reactions to stuttering, adverse impact of stuttering on quality of life, and overall adverse impact of stuttering. These positive findings are consistent with previous research indicating reduced adverse impact for adults who participate in stuttering support activities

Table 4. Aim 3 descriptive statistics and *p* values.

Variable	First-time campers Returning campers									
	General information		Reactions to stuttering		Communication		Quality of life		Mean impact score (overall)	
Precamp median	2.47	2.46	2.45	2.18	2.20	2.10	1.67	1.49	2.28	2.11
Postcamp median	2.47	2.46	2.05	2.00	2.00	2.18	1.40	1.53	2.05	1.98
<i>p</i> value within group	.340	.386	.006	< .001	.005	.923	.077	.138	.001	.041
<i>p</i> value between groups	.640		.777		.045		.416		.086	

Note. The bolded values indicate significant effects.

Figure 4. Distribution of first-time campers' pre and post OASES subtest scores and overall impact. Each box and whisker plot shows the interquartile range (box) with the median (horizontal bar). The whiskers (vertical lines) extend 1.5 interquartile ranges above and below the upper and lower quartiles, respectively. The outliers (circular dots) are greater than 1.5 interquartile ranges above or below the interquartile range. * $p < .05$, ** $p < .01$ (significance level for five pairwise comparisons with overall $\alpha = .05$).



(Trichon et al., 2006; Trichon & Tetnowski, 2011, 2015), as well as research showing that summer camp treatment and support experiences help to reduce the adverse impact of stuttering for children who stutter (Byrd, Chmela, et al., 2016; Byrd, Hampton, et al., 2016; Gerlach et al., 2019).

For Aim 2, there were no statistically significant differences in the changes experienced by school-age and teenage campers; both age groups experienced positive and comparable improvements in negative reactions to stuttering and reductions in adverse impact due to stuttering after attending camp. Additionally, school-age campers experienced an added improvement in quality of life. These preliminary findings indicate that support can be helpful for children of all ages, though potentially in different ways depending upon age. Additional research is necessary to better understand which components of the support experience may be most beneficial for each age group.

For Aim 3, we discovered that both first-time campers and returning campers demonstrated significant reductions in negative reactions to stuttering and the overall adverse impact of stuttering. First-time campers additionally showed an improvement in communication attitudes. These findings are consistent with previous research looking at first-time attendees of summer camp therapy programs (Byrd et al., 2018). While positive changes were seen in subsequent years, it seems that participating in support has the largest impact on communication

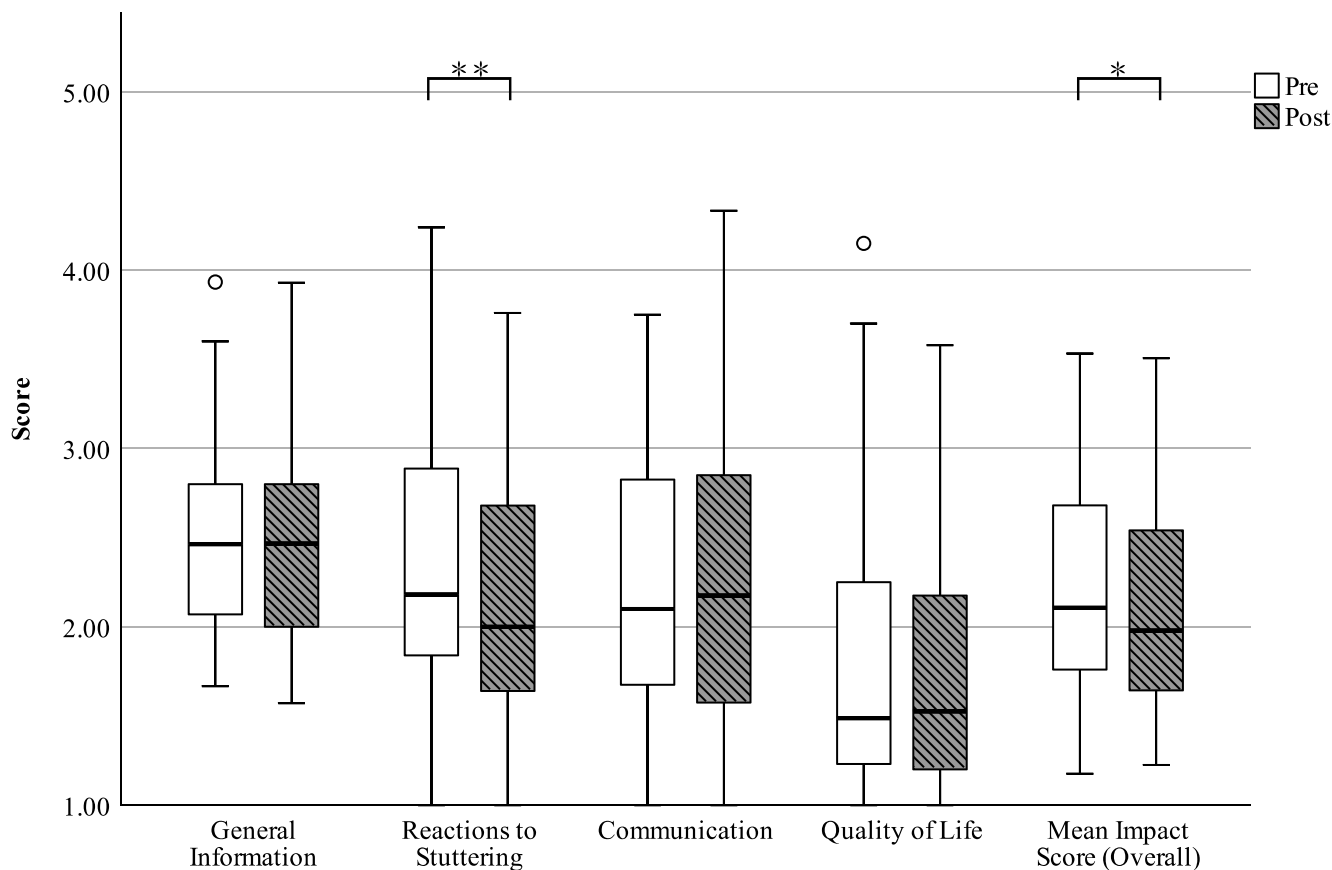
attitudes in the first year, when the support experience is novel.

Finally, for Aim 4, we found that improvements were seen across all subsections of the OASES from precamp to the 6-month follow-up. Improved quality of life and reduced adverse impact of stuttering were not only maintained 6 months post camp but also significantly improved pre-camp to follow-up. Again, the findings that changes are either maintained or continue to improve after the conclusion of the support experience are consistent with previous findings for participation in support experiences (Gerlach et al., 2019).

Benefits of a Support-Based Summer Camp Program for Children Who Stutter

As noted, Camp SAY does not directly address stuttering modification or speech modification strategies, incorporate individualized speech-related goals, or otherwise provide a systematic speech therapy program. Furthermore, Camp SAY does not include targeted activities that specifically focus on any of the constructs addressed by the OASES. Nevertheless, improvements were observed in the campers' reactions to stuttering, communication abilities, quality of life, and overall impact. Therefore, it is hypothesized that these positive changes observed were associated with the support experience rather than focus on speech-

Figure 5. Distribution of returning campers' pre and post OASES subtest scores and overall impact scores. Each box and whisker plot shows the interquartile range (box) with the median (horizontal bar). The whiskers (vertical lines) extend 1.5 interquartile ranges above and below the upper and lower quartiles, respectively. The outliers (circular dots) are greater than 1.5 interquartile ranges above or below the interquartile range. * $p < .05$, ** $p < .01$ (significance level for five pairwise comparisons with overall $\alpha = .05$).



related or stuttering-related factors. This finding is consistent with prior literature on stuttering support: Being with other people who stutter, sharing lived experiences, and experiencing complete acceptance of stuttering are valuable for people who stutter. Although it is not possible to determine which specific aspects of the camp program may be associated with the observed changes, present results suggest that attending a summer camp program like Camp SAY—that is, one that is focused on stuttering support and in which openly stuttering is completely acceptable and accepted—

provides an opportunity for children who stutter to experience these commonly reported benefits of support group participation (Gerlach et al., 2019).

Implications for SLPs and Children Who Stutter

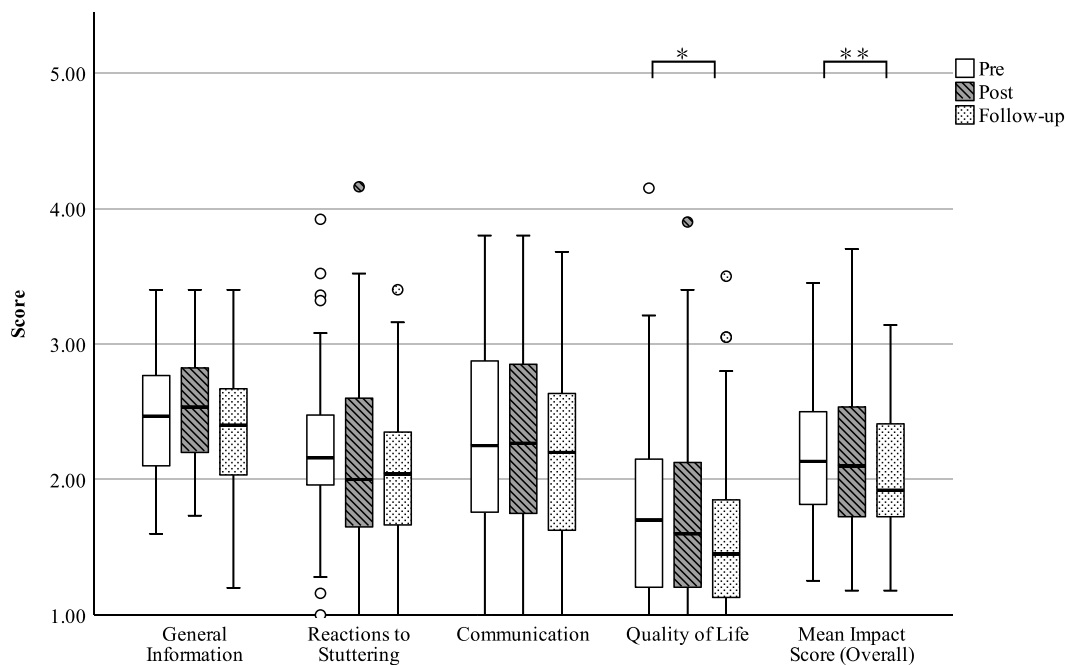
Support activities are associated with beneficial changes in reactions to stuttering, quality of life, and the overall impact of stuttering. Therefore, in order to ensure that children who stutter are receiving optimal intervention

Table 5. Aim 4 descriptive statistics and p values.

Variable	General information	Reaction to stuttering	Communication	Quality of life	Mean impact score (overall)
Precamp median	2.47	2.16	2.25	1.70	2.13
Postcamp median	2.53	2.00	2.27	1.60	2.10
Follow-up median	2.40	2.04	2.20	1.45	1.92
p value across time	.075	.197	.095	.021	.006

Note. The bolded values indicate significant effects.

Figure 6. Distribution of pre, post, and follow-up OASES subtest scores and overall impact scores. Each box and whisker plot shows the interquartile range (box) with the median (horizontal bar). The whiskers (vertical lines) extend 1.5 interquartile ranges above and below the upper and lower quartiles, respectively. The outliers (circular dots) are greater than 1.5 interquartile ranges above or below the interquartile range. * $p < .05$, ** $p < .01$ (significance level for five pairwise comparisons with overall $\alpha = .05$).



that addresses all components of stuttering, it is important for SLPs to create opportunities for their clients to meet other children who stutter in a supportive environment. This could be in the form of a support group outside of school or grouping children who stutter together during school speech therapy.

Findings from this study also have implications for how SLPs can work to foster generalization of therapy gains to other settings. The Communication in Daily Situations section of the OASES, which considers functional communication at school, during social interactions, and in home life, only showed positive changes for first-time campers. This may be due to the fact that those everyday situations are different from the situations experienced at summer camp. Indeed, one of the reasons that children may experience positive changes during camp is the fact that the safe, stuttering-friendly environment that children experience at camp is different from what they typically experience in their school and home environments. To assist with greater generalization to these other settings, clinicians and parents may benefit from emulating the supportive environment created in the camp setting. If acceptance of stuttering helps to improve children's quality of life in the camp setting, it is likely that it will also yield improvements in the "real-world" setting.

Implications for Camps and Support Groups

Campers' knowledge about their speech, their own stuttering, and stuttering in general was unchanged following attendance at Camp SAY. This stands in contrast to

prior studies, which did report changes in the *General Information* section of the OASES (Gerlach et al., 2019). This finding is not surprising, given that direct education about stuttering is not explicitly addressed at Camp SAY. Still, future refinements of the camp program may benefit from including more directed conversations about stuttering or from programming that encourages self-reflection about stuttering, in order to facilitate changes in campers' knowledge about stuttering. Similarly, the previously mentioned finding that improvements in functional communication did not generalize to real-world situations also has implications for support organizations and camp organizers. Specifically, to further increase the potential value of support-based camp experiences, organizations should consider ways of incorporating programming that is specifically focused on improving generalization of gains to daily situations.

Limitations

Over the summers when data were retrospectively analyzed (2013, 2015, and 2016), 304 campers who stutter attended camp. Data for this study were collected only from 109 of these participants, however. Much of this missing data occurred in 2013, when only 24 out of 88 campers provided usable data. The reasons for this included incomplete pre- and/or postcamp OASES responses and the fact that several groups of campers were inadvertently not given the postsurvey on the final day of camp. Importantly, these data are missing not due to self-selection or to a decision on the

part of individual campers to avoid completing the OASES—such causes for missing data might introduce bias in the results. In this case, the children who completed the OASES reflect a random and representative sample of the campers in attendance in 2013, with missing data entirely due to factors unrelated to stuttering or to the experiences of campers.

Across the years in which data were collected for this study, some campers skipped portions of the OASES. It is possible that those campers may have done so because they had particularly negative reactions to stuttering and feared that completing the testing would be too difficult or painful. Fortunately, however, almost all of the missing data can be attributed to ordinary, unpredictable aspects of life at a large summer camp, such as children not being with their group when posttesting occurred, leaving camp early, or not having the opportunity to complete the OASES due to schedule changes. This study was retrospective in nature, and data collection was not the main objective of the camp experience. Still, these missing data may represent a self-selection bias of participants with higher confidence that should be accounted for in future research.

Another potential limitation is that the camp counselors and present authors did not seek to control for a variety of factors that may have affected the results. For example, while participants were not active in other support experiences *during* their attendance at Camp SAY, it is not known if they were active in other support group activities or treatment before or after camp that may have affected their experiences. It is possible that other support or treatment experiences may have affected the durability of change, though the findings were generally consistent across participants and it is unlikely that *all* campers participated in other relevant support or treatment activities in the 6 months after they attended camp. Thus, it is likely that at least some of the benefits can be traced back to camp participation. Future research should seek to control for such factors in order to more specifically examine the potential benefits of support-based camp experiences. One factor that particularly needs to be considered is prior support or treatment activities, especially for first-time campers, that may have resulted in a particular child having a “less-novel” experience of stuttering support even though it was their first time at this particular camp. Finally, future research should consider the experience of children who stutter who participate in “regular” summer camps that do not include a stuttering support component. This would help to differentiate whether observed benefits are associated with the support aspects of Camp SAY or simply being away at a summer camp.

Future Directions and Conclusions

This study was intended to be a first step in evaluating the role of support-based summer camp for children who stutter. In the future, the effects of support activities for children who stutter should be examined in a prospective study that would allow for collection of more thorough background and demographic information, while controlling for participation in speech therapy and other support

experiences. Study replication is also important to confirm these preliminary findings and further explore the outcomes. Another valuable step would be to assess the durability of changes beyond 6 months.

Nevertheless, present findings highlight the value of and need for additional research on the potential benefits of support-based camp experiences for children who stutter. Given the positive changes observed during a short-term, 2-week, support experience, the effects of ongoing year-round support services should be considered. A greater understanding of the benefits of stuttering support will provide more information about the relationship between support experiences and the adverse impact of stuttering, ultimately allowing SLPs to more appropriately recommend support services to their students who stutter. For now, these preliminary results, combined with prior research on support activities for children who stutter, suggest that SLPs can be confident in referring their clients to support organizations and that participation in support groups can have a beneficial effect in the lives of young children who stutter.

References

- Blood, G. W., & Blood, I. M. (2016). Long-term consequences of childhood bullying in adults who stutter: Social anxiety, fear of negative evaluation, self-esteem, and satisfaction with life. *Journal of Fluency Disorders, 50*, 72–84. <https://doi.org/10.1016/j.jfludis.2016.10.002>
- Blood, G. W., Blood, I. M., Tramontana, G. M., Sylvia, A. J., Boyle, M. P., & Motzko, G. R. (2011). Self-reported experience of bullying of students who stutter: Relations with life satisfaction, life orientation, and self-esteem. *Perceptual and Motor Skills, 113*(2), 353–364. <https://doi.org/10.2466/07.10.15.17.PMS.113.5.353-364>
- Borkman, T. (1999). *Understanding self-help/mutual aid: Experiential learning in the commons*. Rutgers University Press.
- Boyle, M. P. (2013). Psychological characteristics and perceptions of stuttering of adults who stutter with and without support group experience. *Journal of Fluency Disorders, 38*(4), 368–381. <https://doi.org/10.1016/j.jfludis.2013.09.001>
- Byrd, C., Chmela, K., Coleman, C., Kelly, E., Reichhardt, R., & Irani, F. (2016). An introduction to camps for children who stutter: What they are and how they can help. *Perspectives of the ASHA Special Interest Groups, 1*(4), 55–69. <https://doi.org/10.1044/persp1.SIG4.55>
- Byrd, C., Gkalitsiou, Z., Werle, D., & Coalson, G. A. (2018). Exploring the effectiveness of an intensive treatment program for school-age children who stutter, Camp Dream. Speak. Live.: A follow-up study. *Seminars in Speech and Language, 39*(5), 458–468. <https://doi.org/10.1055/s-0038-1670669>
- Byrd, C., Hampton, E., McGill, M., & Gkalitsiou, Z. (2016). Participation in Camp Dream. Speak. Live: Affective and cognitive outcomes for children who stutter. *Journal of Speech Pathology & Therapy, 1*(3), 1–10.
- Camp SAY. (2018). *Camp SAY*. <https://www.campsay.org>
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Erlbaum.
- Ezrati-Vinacour, R., Platzky, R., & Yairi, E. (2001). The young child’s awareness of stuttering-like disfluency. *Journal Speech,*

- Language, and Hearing Research*, 44(2), 368–380. [https://doi.org/10.1044/1092-4388\(2001\)030](https://doi.org/10.1044/1092-4388(2001)030)
- Gerlach, H., Hollister, J., Caggiano, L., & Zebrowski, P. M.** (2017). *Outcomes of attending a support-organization convention for young people who stutter*. Poster presented at the 11th Oxford Dysfluency Conference.
- Gerlach, H., Hollister, J., Caggiano, L., & Zebrowski, P. M.** (2019). The utility of stuttering support organization conventions for young people who stutter. *Journal of Fluency Disorders*, 62, 105724. <https://doi.org/10.1016/j.jfludis.2019.105724>
- Gielen, R. [Producer] & Alden, M. [Producer]** (2019). *My beautiful stutter* [Motion picture]. Michael Alden Productions.
- Guitar, B.** (2019). *Stuttering: An integrated approach to its nature and treatment* (5th ed.). Wolters Kluwer.
- Hunt, B.** (1987). Self-help for stutterers—Experience in Britain. In L. Rustin, H. Purser, & D. Rowley (Eds.), *Progress in the treatment of fluency disorders* (Vol. 1, pp. 198–212). Taylor & Francis.
- Langevin, M., Bortnick, K., Hammer, T., & Wiebe, E.** (1998). Teasing/bullying experienced by children who stutter: Toward development of a questionnaire. *Contemporary Issues in Communication Science and Disorders*, 25, 12–24.
- Langevin, M., Kleitman, S., Packman, A., & Onslow, M.** (2009). The Peer Attitudes Toward Children who Stutter (PATCS) scale: An evaluation of validity, reliability and the negativity of attitudes. *International Journal of Language & Communication Disorders*, 44(3), 352–368. <https://doi.org/10.1080/13682820802130533>
- Manning, W. H., & Dillolo, A.** (2018). *Clinical decision making in fluency disorders* (4th ed.). Plural.
- McClure, J. A., & Yaruss, J. S.** (2003). Stuttering survey suggests success of attitude-changing treatment. *The ASHA Leader*, 8, 3–19. <https://doi.org/10.1044/leader.FTR2.08092003.3>
- Murphy, W. P., Yaruss, J. S., & Quesal, R. W.** (2007a). Enhancing treatment for school-age children who stutter I. Reducing negative reactions through desensitization and cognitive restructuring. *Journal of Fluency Disorders*, 32(2), 121–138. <https://doi.org/10.1016/j.jfludis.2007.02.002>
- Murphy, W. P., Yaruss, J. S., & Quesal, R. W.** (2007b). Enhancing treatment for school-age children who stutter II. Reducing bullying through role-playing and self-disclosure. *Journal of Fluency Disorders*, 32, 139–162. <https://doi.org/10.1016/j.jfludis.2007.02.001>
- Plexico, L. W., Manning, W. H., & Dillolo, A.** (2005). A phenomenological understanding of successful stuttering management. *Journal of Fluency Disorders*, 30(1), 1–22. <https://doi.org/10.1016/j.jfludis.2004.12.001>
- Rosenthal, R.** (1994). Parametric measures of effect size. In H. Cooper & L. Hedges (Eds.), *The handbook of research synthesis* (Vol. 621, pp. 231–244). Russell Sage Foundation.
- SAY: The Stuttering Association for the Young.** (2018). *SAY: The Stuttering Association for the Young*. <https://www.say.org>
- Tichenor, S. E., & Yaruss, J. S.** (2019). Group experiences and individual differences in stuttering. *Journal of Speech, Language, and Hearing Research*, 62(12), 4335–4350. https://doi.org/10.1044/2019_JSLHR-19-00138
- Trichon, M., & Tetnowski, J.** (2011). Self-help conferences for people who stutter: A qualitative investigation. *Journal of Fluency Disorders*, 36(4), 290–295. <https://doi.org/10.1016/j.jfludis.2011.06.001>
- Trichon, M., & Tetnowski, J.** (2015). *Self-help conferences and change in the experience of stuttering: Preliminary findings and implications for self-help activities*. Poster presented at the International Fluency Association.
- Trichon, M., Tetnowski, J., & Rentschler, G.** (2006). Perspectives of participants of self-help groups for people who stutter. In J. Au-Yeung & M. M. Leahy (Eds.), *Research, treatment, and self-help in fluency disorders: New horizons. Proceedings of the Fifth World Congress on Fluency Disorders* (pp. 171–176). International Fluency Association.
- Vanryckeghem, M., Brutten, G. J., & Hernandez, L. M.** (2005). A comparative investigation of the speech-associated attitude of preschool and kindergarten children who do and do not stutter. *Journal of Fluency Disorders*, 30(4), 307–318. <https://doi.org/10.1016/j.jfludis.2005.09.003>
- Yaruss, J. S., Coleman, C. E., & Quesal, R. W.** (2012). Stuttering in school-age children: A comprehensive approach to treatment. *Language, Speech, and Hearing Services in Schools*, 43(4), 536–548. [https://doi.org/10.1044/0161-1461\(2012\)11-0044](https://doi.org/10.1044/0161-1461(2012)11-0044)
- Yaruss, J. S., & Quesal, R. W.** (2006). Overall Assessment of the Speaker's Experience of Stuttering (OASES): Documenting multiple outcomes in stuttering treatment. *Journal of Fluency Disorders*, 31(2), 90–115. <https://doi.org/10.1016/j.jfludis.2006.02.002>
- Yaruss, J. S., & Quesal, R. W.** (2016). *OASES: Overall Assessment of the Speaker's Experience of Stuttering: Manual*. Stuttering Therapy Resource.
- Yaruss, J. S., Quesal, R. W., & Reeves, L.** (2007). Self-help and mutual aid groups as an adjunct to stuttering therapy. In E. G. Conture & R. F. Curlee (Eds.), *Stuttering and related disorders of fluency* (3rd ed., pp. 256–276). Thieme Medical Publishers.
- Yaruss, J. S., Quesal, R. W., Reeves, L., Molt, L. F., Kluetz, B., Caruso, A. J., McClure, J. A., & Lewis, F.** (2002). Speech treatment and support group experiences of people who participate in the National Stuttering Association. *Journal of Fluency Disorders*, 27(2), 115–134. [https://doi.org/10.1016/S0094-730X\(02\)00114-6](https://doi.org/10.1016/S0094-730X(02)00114-6)

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