Critical Review:
How does participation in support groups impact psychosocial outcomes for people who stutter?

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This review examined the current literature on the effect of stuttering support groups (SGs) on the psychosocial outcomes of adolescents and adults who stutter. Study designs include a non-randomized between-groups clinical trial, a within-group study, two single-group studies, and one qualitative research study. Overall, the findings from this critical review are moderately suggestive that participation in support groups can improve the psychosocial well-being of people who stutter. However, the extent of improvement and specific psychosocial variables affected differ across studies.

Introduction

Many people who stutter (PWS) experience a variety of psychosocial stressors related to their stuttering that can negatively impact their participation in social interactions and their overall quality of life (Boyle, 2015). "Elevated levels of anxiety [among PWS] are thought to manifest in early adolescence and intensify in adulthood" (Gerlach, et al., 2019, p.2).

Speech-language pathologists (SLPs) must play a role in identifying stressors and helping to minimize client anxiety related to stuttering (CASLPO, 2014). SLPs should also "provid[e] experiences that will alter attitudes or beliefs that have a negative impact on fluency" (CASLPO, 2014).

Participation in support groups is one option for addressing the psychosocial needs of PWS. In a survey study by Yaruss, et al. (2002), the majority (93.8%) of respondents reported that involvement in support groups for PWS "somewhat" to "very" positively affected their self-image.

Despite this finding, Yaruss et al. (2002) also reported that only 9 out of 16 study participants currently in speech therapy were encouraged to attend a support group by their SLP. The reasons for SLPs reluctance in encouraging support group participation were not outlined. However, it is clear that the role of support groups in bringing about attitudinal and emotional changes in PWS needs to be better understood by researchers and practicing clinicians in order to support efficacy of the recommendation.

For the purpose of this review, the term *support group* (SG) refers to any peer interactions with greater than two people. This may include face-to-face interactions or online communities. Much of the literature in this area looks at participation in conventions/conferences for PWS. These conferences are distinguished from other forms of group therapy in that they are run by other PWS, not by SLPs or other professionals. Boyle (2015) clarifies that these groups are often run with "the intent that group members can share experiences, learn from others, receive emotional support, and also encourage and help their peers" (p.3).

Psychosocial outcomes is a broad term that can include a wide range of psychological and social constructs. To avoid limiting the findings of this review, any constructs related to the affective well-being of the PWS, and the resulting impacts on participation and quality of life, are included. Speech-related outcomes and secondary characteristics of stuttering are excluded, although they likely also impact and are impacted by psychosocial variables in PWS.

Objectives

The primary objective of this critical review is to evaluate the existing literature on the impact that participation in support groups has on the psychosocial well-being of adolescents and adults who stutter.

Methods

Search Strategy

Several computerized databases, including SCOPUS, PubMed, and Google Scholar were searched for articles on the topic of interest. The following keywords were used to narrow the search parameters:

(stuttering) AND [(support group) OR (self-help support group) OR (conferences)] OR (conventions)] AND [(psychosocial) OR (quality of life)]

The search was limited to articles written in English between 2000 and 2019.

Selection Criteria

Studies selected for inclusion were required to examine the psychosocial impacts of stuttering support group participation. The search excluded articles about young children who stutter (under 10 years of age).

Data Collection

The results of this literature search yielded five articles pertaining to the topic of interest. The study designs include a non-randomized between-groups clinical trial, a within-groups study, two single-group studies, and one qualitative research study.

Results

Boyle (2013) conducted a non-randomized clinical trial comparing PWS who have support group (SG) experience to those without support group experience across a range of psychological factors. A web-based survey was distributed to adults who stutter who had participated in a previous study by this author. The survey consisted of several instruments measuring self-esteem, self-efficacy, life satisfaction, self-stigma, and perceived stuttering severity. Qualitative data was also collected that addressed participants' reasons for joining the SG, perceptions of the cause of stuttering, beliefs about the future course of stuttering, and views about the importance of speech fluency. A total of 279 participants completed the survey, 175 with a history of participation in SGs and 104 without SG experience.

Results indicated that the majority of participants with SG experience (74.1%) found support groups extremely or moderately helpful. The only psychological variable with a statistically significant difference between the groups was self-stigma, revealing that PWS with SG experience were less likely to internalize stigmatizing beliefs about themselves (small effect size). The subgroup of participants who reported joining a SG to help others were found to have statistically higher self-esteem and life satisfaction as well as lower perceived stuttering severity and self-stigma (small-moderate effect sizes). Those with SG experience also reported that they believed they would stutter for the rest of their lives and viewed fluent speech as less important.

Boyle (2013) provided detailed descriptions of each psychological variable of interest to avoid any misinterpretation of the data. Excellent validity and reliability were reported for most of the instruments. When not available, the author provided theoretical explanations for the measurement chosen.

To account for the difference in group sizes, Levine's test for equality of variances was employed, finding that equality could be assumed for each comparison. Appropriate statistical analyses were conducted. Boyle (2013) also analyzed and reported good statistical power.

The study design is appropriate for addressing the author's purpose, as it appropriately compared the two groups. However, there are a few limitations; it is unclear if those who choose to seek out SGs are different from those who do not in the psychological variables addressed. Boyle (2013) also acknowledged some of the study's limitations. Without knowing the response rate, response bias may impact generalization of the results. Also, assuming any causal relationships is prevented by the cross-sectional design.

Overall, this study provides a suggestive level of evidence when taking into account the design, strengths and weaknesses. The results demonstrated preliminary evidence that participation in SGs may impact the well-being of PWS across some psychosocial parameters. However, as participation in SG was the only variable controlled, it may be that other underlying personality traits or other forms of social support could also be playing a role in psychosocial outcomes.

Gerlach, Hollister, Caggiano and Zebrowski (2019) led a within-groups study to determine if young people who stutter experience any cognitive or affective changes after attending a stuttering support group convention. Twenty-two participants (ranging in age from ten to eighteen) attended the 2016 FRIENDS annual convention. This convention is designed to educate and empower young people who stutter as they participate in meaningful experiences with their peers. Family members and SLPs are often also included in FRIENDS conferences. Study participants completed the Overall Assessment of the Speaker's Experience with Stuttering (OASES) pre-convention, post-convention and at three months follow-up. Semi-structured online video interviews were also conducted with seven of the participants following the convention to add more depth to the quantitative findings.

The quantitative results showed that the overall score and three of the four subsection scores on the OASES showed statistically significant change from pre- to post- conference (small effect size). These subsections included *General Information*, *Reactions to Stuttering* and *Communication in Daily Situations*. The *Quality of Life* subsection, which looks at "how stuttering interferes with various domains of life", was not statistically significant (Gerlach, et al., 2019, p.4). Item by item analysis indicated the largest improvement in (1) difficulty talking in different contexts, (2) confidence and knowledge about stuttering, and (3) negative reactions to stuttering. *Reactions to Stuttering* was the only subsection with changes that were maintained from post- to three months follow-up.

The qualitative results suggested that participants felt a sense of community at the convention that helped to facilitate personal growth, increase their self-acceptance and normalize their stuttering.

The pool of participants was limited to those already enrolled in the FRIENDS conference, making generalizability of the results challenging. The authors provided inclusion and exclusion criteria and some demographic information (age, sex, ethnic background) for the selected participants; however, demographics were not factored into their analysis. Maximum variation sampling was used to ensure diversity amongst those chosen for the interviews. In order to minimize interviewer bias, Gerlach et al. (2019) choose the author who had not attended the conference and who had no experience with the organization (FRIENDS).

The OASES is a well-established measure of the functional impact of stuttering, with excellent validity and reliably. Appropriate statistical analyses for the quantitative data were employed (Friedman test with poc hoc analysis, Cohen d's effect sizes). The authors outlined in detail the data analysis protocol they use for the qualitative data, including investigator triangulation and member-checking to increase credibility. A script of the structured interview questions was also provided, allowing for replicability of the study.

While appropriate for the authors' purposes, one inherent limitation of within-groups studies is that there is no control group for comparison. It should also be noted that the participants at the younger end of the age range could be psycho-emotionally less mature than those who were older, possibly skewing the results. Furthermore, the inclusion of family members and SLPs in the convention could also confound the results, as we cannot assume changes were due to peer interactions.

The longitudinal design of this study is a strength, as it begins to address whether the positive impact of support group participation is maintained long-term.

Overall, this study is suggestive that participation in conferences for young people who stutter can decrease some of the negative impacts of stuttering. However, this study does not closely examine those psychosocial variables that may be contributing to the component OASES scores. Since most of the participants were Caucasian, all of them were adolescents and none rated their stuttering severity above moderate, generalization to other populations should be done with caution.

Raj and Daniels (2017) examined the differences in how PWS rate their self-esteem, feelings about being a PWS, and levels of support before and after involvement with online stuttering support groups. Forty-two adults who stutter completed an online questionnaire, providing ratings for each psychosocial variable on a 5-point Likert scale and then providing qualitative descriptions for each rating. The authors also sought to look at how online support differs from face-to-face support group participation.

The results of this study showed an increase in self-esteem (t=-4.965, P=.000) and levels of support (t=-2.284, P=.029) after participation in an online support group community. No statistically significant difference in feelings about being a person who stutters was found. Analysis of the qualitative data generated themes related to *helplessness*, *resentment*, *indifference*, *insecurity* and *loneliness* prior to online support community involvement. Themes post-involvement included *helpful*, *acceptance*, *appreciation*, *confidence*, and *comraderie*. Online community involvement was thought to be more *accessible* and provide better *ongoing support* when compared to face-to-face support groups.

Inclusion criteria was outlined, and demographic details on the age, sex, ethnicity and country of origin were provided for each participant. However, response rates were not known based on mass email recruitment, which could impact the statistical significance of the results.

The questionnaire was created only to address the purpose of the study and had never been trialed in previous studies. While the authors attempted to improve the validity of their measure by having three doctorate level experts in stuttering review the questions, no proof of validity and reliability was reported. Furthermore, it was unclear if definitions for the multidimension constructs (eg. self-esteem) were provided to participants, calling into question the consistency of how they were interpreted by the respondents (construct validity).

The quantitative data was analyzed appropriately, using paired samples t-tests. Analysis of the qualitative data was based on grounded theory. Raj and Daniels (2017) attempted to limit rater bias by discussing biases prior to analysis, by choosing investigators with varied backgrounds and through investigator triangulation.

One major limitation of this study is that the scores being compared were all made retrospectively, calling into question the accuracy of the respondent's feelings prior to online community involvement (response bias); they may be overestimating the amount of change they see in themselves since they are making the ratings post-involvement. As a result, this single group, post-test only design is not appropriate for the purpose of this study.

The use of an online questionnaire may also limit the respondents to those who have access to a computer/mobile device, potentially biasing the results to only those with higher socioeconomic status (SES). Raj and Daniels (2017) also acknowledged that these findings cannot be generalized to all online communities.

Based on the flaws in the design type and the other outlined limitations, the findings of this study are only slightly suggestive that involvement in online support groups are beneficial in providing psychosocial support for PWS.

Boyle (2015) conducted a cross-sectional single group study examining which psychosocial factors predict quality of life in PWS. Only those related to self-help support groups (SHSG) are relevant to the current question. Participants included adults who stutter and were recruited from Board Certified Specialists in fluency disorders and adult chapters of the National Stuttering Association. A total of 249 participants completed a web-based survey that included a variety of self-report tools measuring a range of psychosocial constructs.

The results of this study found that quality of life was positively correlated with the level of SHSG participation (medium effect size), consistency of attendance in SHSGs, and years attending SHSGs (small effective size). The level of self-help support group participation was positively correlated with self-esteem and self-efficacy (small effect size). However, self-help support group participation was not a strong predictor of quality of life in PWS, as some of the other psychosocial variables (family support and empowerment) accounted for more of the variance.

The author included an extensive rationale for the study and detailed definitions for each of the psychosocial constructs. A description and rationale for each measurement tool was provided, with psychometric properties reported where available.

Boyle (2015) controlled for demographic and stuttering related parameters, including age, gender, previous and current treatment involvement, previous SHSG experience, current SHSG involvement, and self-rated stuttering severity. Appropriate statistical analyses were conducted (ANOVA, bivariate correlational analysis, multiple/hierarchical regression).

A single group study is an appropriate choice for determining correlational relationships between variables. One limitation of this study could be sociodemographic bias due to the use of a web-based survey. Despite being unable to determine causation from this data, this study still provides a suggestive level of evidence based on its strong statistical analyses, replicability, and sound theoretical rationale.

Trichon and Tetnowski (2011) conducted a qualitative investigation to examine the personal experiences of PWS who have attended self-help conferences. Twelve adults who stutter and have attended a self-help conference participated in semi-structured interviews between four- and eighteen-months post-conference.

Themes that emerged related to socializing opportunities, affiliation, redefining oneself and post-conference disclosure. The authors concluded that the experiences of their participants supported the utility of self-help conferences in reducing the negative impacts of stuttering.

While inclusion criteria were outlined, how the final participants were selected was not. The gender and age of participants was reported, but not information on cultural background or SES, impacting the replicability and generalizability of this study. The semi-structured interview method was appropriate for the design type and addressing the research question. However, there was a large range in when interviews occurred post-conference, which could have impacted the responses of participants and was not accounted for in the analysis. Furthermore, the interview questions were not documented, impacting the replicability of the study. This oversight also precludes analysis of the reliability and validity of the questions.

Trichon and Tetnowski (2011) provided very minimal procedural or theoretical detail on how the responses were analyzed to procure the main themes (interpretive phenomenological analysis). No consideration was given to investigator biases. The main themes that emerged were defined and discussed briefly, with direct quotes from the participants. Minor themes also emerged but were not discussed.

Considering the lack of replicability and lower quality design, the findings of this study are only slightly suggestive of the impact of self-help support group participation on psychosocial outcomes for PWS.

Discussion

After analyzing the current literature, a moderately suggestive level of evidence exists that participation in support groups may positively impact the psychosocial well-being of PWS. The specific psychosocial variables showing improvement, the extent of improvement and the long-term effects remain unclear and differ across the studies.

While much of the quantitative data reported only small effect sizes or insignificant positive correlations, none of the studies reported any negative correlative data to suggest that PWS experience worse psychosocial challenges post- SG involvement. Similarly, the qualitative data also reported themes that were largely positive. While it is entirely possible that those who have had negative experiences with support groups choose not to participate in these studies or that researcher positionality in some of the studies has led to qualitative bias, the available evidence would tentatively suggest that PWS have mostly positive experiences with support groups.

However, limitations in the designs and methodologies used make generalizability of these findings problematic. Only one of the five studies included a control group, vastly weakening the strength of the findings. Several of these studies also demonstrated potential bias in how they selected their participants. By doing mass recruitment via the internet, it is unclear if participants who self-enroll (in SGs and in these studies) demonstrate an underlying 'readiness' and if they differ in SES, which could bias the results.

The ability to compare the data across the studies is also confounded by the range of psychosocial variables chosen. Working definitions of the multidimensional constructs did not always align or were not always provided by the authors. Furthermore, many of the studies used non-standardized tools to measure the psychosocial variables, bringing into question the construct reliability of these measures. All of these limitations should lead researchers and clinicians to be cautious in their interpretation of the findings.

Future Research Considerations

To address many of the weaknesses and gaps in the literature, future research may focus on the following topics:

a) Only one of the studies in this review include a longitudinal design; however, the authors only followed up at three-months. Future studies should use a longitudinal approach to address the long-term effects of support group participation.

b) Similarly, the dosage of support group involvement also requires further research. Looking into how the frequency and consistency of participation affects psychosocial outcomes would be very useful for clinicians wanting to recommend SG interactions to their clients.

c) Studies should address any 'readiness' factors that may be impacting when PWS choose to seek out support groups. Research in this area could not only improve how researchers select their participants but also provide practicing SLPs with things to consider when deciding if their client is 'ready' for a SG approach.

d) The field would also benefit from further research comparing different "delivery methods" for support groups. How does online support differ from face-to-face? What elements of support groups/conventions have the biggest impact on psychosocial well-being? How does support group experience compare to other peer exchanges, such as mentorships between PWS or watching documentaries/reading books about other PWS?

e) While not discussed in this review, Boyle (2015) provided preliminary, correlational evidence to suggest that other factors are bigger contributors to psychosocial well-being than participation in SGs. The interaction between support group involvement and other factors (such as familial support, personality traits, etc.) that may impact psychosocial well-being should also be addressed in future studies.

Clinical Implications

SLPs have a responsibility to address the functional and psychosocial impacts of stuttering with their clients. The current review can provide practicing SLPs with some preliminary evidence to support cautious recommendation of support group participation for addressing the negative affective impact of stuttering. Many authors recommend SLPs use a multidimensional approach to stuttering treatment (Boyle, 2013). Accordingly, the use of support groups to address psychosocial well-being should likely be used in conjunction with other therapy approaches. SLPs should use their clinical judgment to first evaluate the readiness of their clients in order to limit any possible negative consequences of support group participation. To contribute to the available evidence and support clinical recommendations, SLPs should use well-established measures (such as the OASES) to measure client outcomes following support group experiences. SLPs should also have a thorough understanding of how stuttering can impact psychosocial well-being, and when a referral to other professionals may be warranted.

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