The Development of the Strengthening Skills Program for Autistic Adults:

Feasibility & Acceptability

by

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ABSTRACT

The study focuses on the creation of the Strengthening Skills Program (SSP) and its feasibility and acceptability among autistic adults across the lifespan. Over the course of two years, the program has been developed and delivered to autistic adults with the aim of improving quality of life. The program included adapted social skills training from the UCLA Program for the Education and Enrichment of Relational Skills (PEERS) for young adults, adapted mindfulness training from Mindfulness-Based Stress Reduction, and custom executive skills training. Pre- and post-intervention acceptability questionnaires were gathered from 42 participants. Participants were separated into three groups (SSP, PEERS, and Delayed Treatment Control [DTC]; n=14 per group) stratified by age, gender, and if the participant had a program partner who would attend the program alongside as support. All groups were administered over Zoom once per week and lasted for 16 weeks each. The SSP group met for three hours each week and the PEERS group met for an hour and a half. Qualitative analysis was implemented on participant feedback to identify thematic codes related to their experiences with the programs. Overall, results suggest the SSP intervention had significantly higher acceptability ratings compared to PEERS alone and could be a useful addition to the limited interventions available for autistic adults.

TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Autism spectrum disorder (ASD) is a condition where individuals have increased difficulties with social communication, and restrictive and repetitive behaviors and interests (American Psychiatric Association, 2013). Challenges developing and maintaining relationships, and with executive functioning are also common (American Psychiatric Association, 2013). These challenges continue into adulthood and persist throughout many facets of life (Warren et al., 2011). While individuals with autism face a lifetime of difficulties, support for autistic adults is extremely limited. Research suggests that as autistic adults age, they are at risk for cognitive decline (Pagni et al., 2022; Walsh et al., 2022). In addition, they face persistent difficulties with social functioning (Walsh et al., 2019) and reduced quality of life (Braden et al., 2021) compared to neurotypical adults. Yet, nearly all of the evidence-based support programs focus on autistic young-adults.

One of the prevailing models for autistic adult support is to adapt programs that were initially developed for children or teens to be appropriate for young-adults. For example, the UCLA Program for the Education and Enrichment of Relational Skills (PEERS) program was developed in 2005 for teens and consists of weekly 90-minute sessions over the span of 16 weeks (Laugeson et al., 2009). In 2012, this program was adapted for young adults (Gantman et al., 2012), and in both programs autistic participants have a parent attending as their "social coach". Results from the program saw increased social skills knowledge and reduced self-reported loneliness, in addition to caregiver-reported improvements in social skills, social responsiveness, empathy, and

frequency of get-togethers in autistic young-adults (Gantman et al., 2012). The Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) model has also been applied to autistic adults (Mesibov & Shea, 2009). It has reduced serious negative behaviors and increased family satisfaction (Van Bourgondien et al., 2003), as well as improved job retention (Keel et al., 1997). A limitation of this approach is that techniques for children and teens are slightly modified to be more age appropriate for young adults. Therefore, issues that affect middle-age and older adults, such as cognitive decline are not considered.

Another approach for programs that support autistic adults is to focus on employment. One of the earliest efforts by Mawhood and Howlin (1999) included autistic adults ranging from 18 to 55 years of age and achieved improvements in job levels, time at work, and wages compared to a control group. In more recent years, vocational support programs have focused on "transition-age" adults, and does not include middle-age or older adults. The Achieving Competitive, Customized Employment through Specialized Services (ACCESS) program contains training seeking to improve areas of career and transitioning and shows preliminary feasibility, but mixed acceptability (Smith, 2019). Transition-age programs that focus on targets beyond employment alone have been more successful. The Acquiring Career, Coping, Executive Control, Social Skills (a different "ACCESS") Program led to improvements in adaptive skills, increased self-determination, and the development of stress-coping skills in autistic young adults (Oswald et. al, 2017). Lastly, the Transition Support Program increased quality of life and self-determination in autistic young adults (Nadig et al., 2018). Overall, group-based

programs can be efficacious for addressing a variety of challenges in autistic adults, but the support available to middle-age and older autistic adults are limited.

Recently, Groenendijk and colleagues (2023) developed the first support program specifically for middle-age and older autistic adults, and the program was co-designed with autistic adults. Co-design has been an effective approach for previous young-adult programs aimed at improving autistic self-determination skills and quality of life (McDonald et al., 2022). Although the Groenendijk et al. (2023) program for older autistic adults found moderate acceptability, they failed to find improvements in self-efficacy, self-esteem, quality of life, or other outcomes.

A potential approach for improving support programs that include middle-age and older autistic adults is to adapt successful support strategies developed for other aging populations. The Mayo Clinic's Healthy Action to Benefit Independence & Thinking (HABIT) Program is designed for individuals with Mild Cognitive Impairment (MCI; Mayo, 2013). The goal of the program is to provide cognitive rehabilitation and strategies in order to preserve memory and improve quality of life. Similar to PEERS, the HABIT program is group based and involves a partner chosen by the participant. There are additional cognitive compensation training and mindful movement components. Importantly, mindfulness practices, such as Mindfulness-Based Stress Reduction (MBSR), have also shown benefits for autistic adults (including middle-age and older adults) in improving quality of life, mental health, and cognition (Braden et al., 2021; Pagni et al., 2020; Pagni et al., 2022).

The aim of the present study was to develop a multi-component support program to address the persistent and heterogenous needs of autistic adults across the lifespan. We

combined aspects of the PEERS social skills program with mindfulness and executive

skills training inspired by MBSR and HABIT, respectively, to form the Strengthening

Skills Program (SSP). We compared the SSP to the established PEERS program and a

delayed treatment control (DTC) group. Data included feasibility and acceptability

qualitative themes from participant feedback.

CHAPTER 2

METHODS & MATERIALS

Participants

Participants for the pilot study had to be autistic adults who met the criteria of the

Autism Diagnostic Observation Schedule 2 (ADOS-2), administered by a research

member of the Southwest Autism Resource and Resource Center (SARRC). Additionally,

participants had to score over a 70 on the Kaufman Brief Intelligence Test, second edition

(Kaufman, 2004). Exclusion criteria were based on if the participant had any history of

traumatic brain injury, substance abuse, or active suicidality. Other common

comorbidities such as mood disorder and epilepsy were not excluded.

In total, 42 adults (Age=41.43[±13.99] years; 25 male, 17 female) were admitted

into the program along with a program partner (i.e., family/friend) for each participant.

Participants were randomly distributed across two cohorts within three groups: SSP (n =

14), PEERS (active comparator; n = 14), or Delayed Treatment Control (DTC) (n = 14)

stratified by age, gender, and presence of a program partner.

Intervention

Cohort 1 took place from August to December of 2021 and cohort 2 took place

from January to May of 2022, each lasting 16 weeks total. Both the SSP and PEERS

programs were conducted through Zoom in order to circumvent issues surrounding the

pandemic. SSP participants attended weekly 3-hour meetings which focused on derived

social skill techniques from PEERS, mindfulness-based strategies, and cognitive

compensatory strategies, such as habit formation and use of external memory aids, to strengthen executive skills.

Weekly 90-minute sessions of the PEERS program were held for a total of 16 weeks. The program focused on improving social skills from the UCLA PEERS autistic youth program adapted for young-adult autistics. Most of the curriculum remained consistent, except for substitution of the UCLA PEERS videos for roleplays better situated towards older adults. An example of this is moving a group conversation role play to the workplace instead of a high school setting.

Assessments

Two acceptability surveys were sent out throughout the program, one at the midpoint and the other post-program. Midpoint surveys served to adapt the remaining 8 weeks of the program based on responses, while post-program surveys assessed overall acceptability and feasibility through quantitative and qualitative responses. Acceptability composite scores were measured using post-program acceptability surveys developed from Stahmer et al. (2017), with lowest acceptability starting at 1 and highest acceptability being 7. A t-test was used to statistically compare the acceptability composite score in SSP vs PEERS participants with alpha set at 0.05.

Qualitative analyses were measured on the responses of post-program surveys sent to participants. Surveys were open-ended and a total of 9 responses were recorded from the SSP group, and 12 responses were recorded from the PEERS group. The method used was a thematic analysis approach to identify and provide insight into patterns of

meaning (Braun & Clark, 2012). This approach first creates general codes about feedback, which provide a small amount of context and explanation of what a participant describes. For example, if a participant writes about how the program can be extended to other people in any capacity, then the general code may be "participant feels others may benefit from program." After a general coding of all the surveys were completed, common themes across responses were pulled. An example of a theme would be "anyone can benefit from the program," if there are more responses from participants which fit this category. Once the themes are created, they are compiled to be reported.

CHAPTER 3

RESULTS

Demographics & Baseline Differences

There were no significant demographic differences between the groups. In total, the 42 participants (25 male (59.5%) 17 female) in the study had an average age of 41.43(±13.99). Most of the participants were White (n=33: 78.6%), and the other participants were spread amongst Hispanic (n=3), Asian (n=1), Alaska/Indigenous (n=1), two or more races (n=2), and other (n=2).

Acceptability Rating

There are 21 total participant responses from the SSP (n=9) and PEERS (n=12). In total, SSP acceptability composite score was 6.49 with a standard deviation of 0.42. PEERS acceptability composite score was 5.91 with standard deviation of 0.69. Additionally, the participant satisfaction survey for SSP participants ranked significantly higher than PEERS participant satisfaction survey [t(19) = 2.21, p = .04)].

Feasibility

The SSP group had higher attrition of 36% compared to the PEERS group of 14%. This could be attributed to a shorter session duration of 1.5 hours in PEERS, being more feasible than a longer session of 3 hours in the SSP. There were 5 responses from the SSP group and 2 responses from the PEERS group about attrition shown in Table 1.

8

Table 1.

Participant Attrition

	SSP	PEERS
Too busy to participate in program	1	1
Mismatch between program and participant goals	1	0
Participant moved out of state during program	1	1
Significant physical health issue (i.e., COVID-19; surgery)	2	0

Table 1 shows the participant attrition responses among the SSP (n=9) and PEERS

(n=12) participants.

Most of the participant attrition responses were related to a limitation from the

participant in being able to continue in the programs, such as health issues and moving

which affected three SSP participants. One participant from each group noted they were

too busy to continue participation in the program, which could be due to the singular day

and time the program occurred. One SSP participant noted there was a difference in what

the participant wanted out of the program and what the program offered.

Qualitative Analysis

A total of 9 responses from the SSP group and 12 responses in the PEERS group

were analyzed for qualitative themes in feedback surveys. Thematic analysis in Table 2

shows similarities and differences between the SSP and PEERS groups. Both programs

have received feedback about a few limitations with most of the responses being positive.

Table 2.

Qualitative Themes

	SSP	PEERS
Anyone could benefit from the program	✓	
Importance of connecting to other group members	✓	✓
Suggesting increased individualization		✓
Program facilitated understanding of autism and autistic identity	✓	
Suggesting increased focus on autism and autistic identity		✓
Enjoyed program/thankful for program	✓	✓
Supportive environment	✓	✓
Appropriateness of program approach	✓	✓
Limitations of program approach		✓
Appropriateness of program content	✓	✓
Limitations of program content		✓
Limitations of program format (meeting length; duration)	✓	
Benefits and challenges of virtual format	✓	✓
Website improvement	✓	N/A

Table 2 shows the qualitative themes present in feedback surveys among the SSP (n=9)

and PEERS (n=12) participants (Braun & Clark, 2012). Each check mark represents if the

theme was present in the participant responses.

Some unique benefits of the SSP noted are that anyone could benefit from the

program as well as the program facilitated understanding of autism and autistic identity.

Participants reported limitations of the SSP format, mostly due to meeting length.

Additionally, the SSP has a website for participants to access topic slides and keep track

of any progress throughout the duration of the program and needs to improve the website

were noted. The themes present in the SSP column can be interpreted as showing

improvements for autistic adults as well as potential adjustments for future direction of

the SSP.

In the PEERS group, a few themes differ such as participants suggesting

increased individualization and focus on autism and autistic identity. Also, participants

reported limitations of program content and program approach. This is likely due to the

PEERS curriculum prioritizing the improvement of social skills and relationships. While

social improvements are important, participants feel there could be more emphasis on

autism as a whole, taking a more individualized approach to the curriculum. These

limitation themes present in the PEERS column show similarities with the unique

features of the SSP, as well as potential adjustments for future PEERS implementation to

adults across the lifespan. Overall, a supportive environment developed in the program

between participants and their program partners was noted across both groups.

CHAPTER 4

DISCUSSION

Overall, the creation and development of the SSP has shown promising results, with a significantly higher acceptability rating than the established PEERS program. Alternatively, participant attrition in the PEERS program is higher than the SSP, which may suggest future adaptation to the length of the SSP. Thematic consistency among participants of the SSP suggests an improvement in social ability similar to PEERS. Additionally, social relationship improvements were noted among participants in both programs. The SSP appears to have some advantages over PEERS such as a focus on autism and autistic identity. The addition of MBSR and focus on executive functioning may have improved acceptability as well.

Many themes across the SSP aligned with the themes present in previous PEERS studies. In both PEERS for adolescents and young adults, improvement of social ability, social skills, and social knowledge were the main themes present in participant responses (Laugeson et al., 2009; Laugeson et al., 2012). Additionally, the UCLA PEERS program reported these improvements remained after a 14-week follow up. We are currently collecting three- and six-month follow-up data to determine persistence of improvements associated with SSP and PEERS in autistic adults across the lifespan. Although the UCLA PEERS program was designed for a younger audience, both the SSP and PEERS program are feasible interventions for middle-age and older autistic adults with similar themes of improving social abilities.

Another part of the SSP was focusing on improving executive functioning and quality of life in participants, similar to Mayo Clinic's HABIT program and the TEACCH program. Both the HABIT program and the SSP focus on addressing challenges applicable to older adults. Results of the HABIT program showed that participants reported the importance of improving quality of life before and after undergoing the intervention (Barrios et al., 2012). Similarly, the TEACCH program has goals pertaining to increasing executive functioning while decreasing maladaptive behavior (Mesibov & Shea, 2009), which is a focus of the SSP. These outcomes also align with the MBSR portion of the SSP, which can improve quality of life and mental health outcomes in autistic adults (Spek et al., 2013). The ACCESS program also focuses on stress-coping techniques for participants in order to lower stress levels, albeit with a focus on transition-age-related stress issues only (Oswald et. al, 2017). Taken together, the combination of executive skills and stress reduction training may be a particularly powerful approach for improving quality of life for autistic adults across the lifespan.

A potential weakness of the SSP program, compared to other autistic adult support programs, is that it does not explicitly target employment outcomes. Although our findings suggest the SSP is feasible and acceptable for young adults, in addition to middle-age and older adults, there may be a lack of training for issues such as employment that typically affect younger adults to a greater degree. Future iterations of the SSP may benefit from incorporating successful techniques from programs such the Transition Support Program or the ACCESS program (Nadig et al., 2018; Smith et al., 2019). Additionally, there may be potential secondary benefits of the SSP as it currently

13

stands on employment, given the noted improvements in social abilities and relationships, and this warrants investigation in future studies.

Additional Future Directions

While there were similarities in the qualitative themes across both programs, the PEERS program had limitations related to its content and method, while the limitations of the SSP program were related to its format. Thus, the SSP protocol has been revised to include shortened, 2-hour weekly meetings, and 8-week modules with a break in between. This format was delivered to the DTC group. Feasibility, acceptability, and qualitative analyses of this adjusted 2-hour, modular format is in progress. Because these adjustments are in response to previous SSP participants, the revised format is expected to improve feasibility and acceptability. If this is confirmed we will pursue a larger, multi-site clinical trial of the revised SSP program.

Conclusion

The feasibility and acceptability results of the SSP are promising. Altogether, the program was well-received by the participants and their program partners. Qualitative themes explicated the benefits participants experienced, and guided revisions of the SSP. The SSP could become a useful addition to increasing the range of interventions available for autistic adults across the lifespan.

14

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