Cultural Acceptability of ABA Parent Training for ASD

Erin Rotheram-Fuller1*, Kylan Turner2, Jodie Ray3

1Associate Professor, Mary Lou Fulton Teachers College, Arizona State University, USA
2Associate Professor of Practice and Director of the Behavior Analysis, Simmons University, USA
3Research Assistant, Mary Lou Fulton Teachers College, Arizona State University, USA

*Corresponding author: Erin Rotheram-Fuller, Associate Professor, Mary Lou Fulton Teachers College, Arizona State University, P.O. Box 871811, Tempe, AZ 85281, USA

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Abstract

Background: While training in Applied Behavior Analysis (ABA) increases parents’ skills in reducing problem behaviors of their children with Autism Spectrum Disorder (ASD; autistic) and reduces their own parental stress, these programs have not been tailored nor accessible to Spanish-speaking parents, and their acceptability within this population remains unclear.

Method: A 10-week ABA parent training program was delivered to monolingual Spanish-speaking parents (n=11) of children with ASD aged 6-10 years old. The program included an initial assessment, six group and four individual evening meetings delivered exclusively in Spanish, with food, transportation, and childcare. Individual interventions were designed with each family to address a parent nominated target behavior. Child behaviors were monitored weekly using Antecedent-Behavior-Consequence (ABC) recording and the Aberrant Behavior Checklist and Parent Stress Index was administered before and after the intervention.

Results: There was high attendance (84.6%) across sessions overall. A wide range of behavioral challenges was reported; approximately 78% of parents found the intervention to be acceptable and saw reduced problem behavior. Parental stress was also significantly reduced post-intervention.

Conclusions: Adaptations to existing ABA parent training interventions are needed to better support Spanish-speaking families of children with ASD, and acceptability of these interventions should be an ongoing part of an iterative intervention delivery process.

Keywords: ABA; Parent training; Autism; Cultural acceptability; Intervention acceptability

Introduction

Children with autism spectrum disorders (ASD; autistic) frequently display a wide range of behaviors that can impact daily individual and family functioning. Parents are responsible for managing and shaping these behaviors over time, yet receive little training and support in how to address behavior problems. This is particularly true for monolingual Spanish-speaking parents of autistic children. Few agencies designed to serve autistic children provide support in Spanish [1]. Supporting parents can be critical in giving children the assistance they need, and can help parents navigate unwanted behaviors as they arise. Because caregivers spend more time with their children than providers throughout a child’s life, training caregivers to be intervention agents increases the potential for ongoing positive behavior and skill development. This paper examines the acceptability of an adaptation of an evidence-based parent training program for monolingual Spanish-speaking parents, to examine willingness to use recommended ABA interventions, as well as resulting changes in child behavior and parent stress as a result of intervention.

Parent Training is Effective

Children with ASD can display a wide range of behaviors that impact their development and environment. These behaviors may
include being withdrawn in social situations, as well as aggression toward others or self-injury, hyperactivity, non-compliance, property destruction, and tantrums [2,3]. Applied Behavior Analysis (ABA) is a scientifically-supported methodology, founded on principles and concepts of behavior analysis, used to improve children’s behavior; ABA focuses on teaching new skills [4] and decreasing challenging behaviors [5]. ABA is the recommended treatment for children with ASD [6]. Training in ABA for parents of children with ASD can provide support for both parents and their children [7].

Specifically, when ABA training was delivered to caregivers of autistic children, researchers have found reduced feeding issues and parental stress [8] as well as increased skill generalization across settings for children [9]. Building on this evidence, several larger-scale randomized control trials have published results supporting the efficacy of parent training to decrease disruptive behavior in young autistic children [7,10,11]. In fact, parent training in combination with medication was shown to be significantly more beneficial on improving child behaviors than medication alone [12]. Despite this strong evidence suggesting the feasibility and efficacy of ABA parent training, these studies were conducted primarily with English-speakers. ABA parent training has not been studied well with non-English speaking populations or monolingual Spanish-speakers, in particular.

Challenges to ABA Parent Training among Spanish-Speaking Families

In addition to failing to deliver services in Spanish to parents who are primarily Spanish-speaking [13], there are many other challenges to accessing consistent and effective behavioral health services in the United States. A non-exhaustive list of these difficulties include: language barriers in written or oral communication (limiting potential for education and/or effective advocacy to meet needs), lack of access to the same information English-speakers have, resource scarcity (i.e. a dearth of high quality therapists speaking the language), fears about immigration status resulting in avoidance of access to formal systems, cultural attitudes and perspectives resulting in suspicion or caution toward formal systems serving families or about the ASD diagnosis itself, and potentially many more [14].

Furthermore, therapies such as ABA that were developed based on white, middle-class populations fail to account for differences in values, customs, child-rearing traditions, expectancies for child and parent behavior, and distinctive stressors and resources associated with different cultural groups. This failure contributes to a negative effect on participation, engagement, and intervention outcomes [15]. Due to these many (often-compounded) challenges, this population is difficult to enroll and maintain in research studies [16]. Few families ever receive hands-on applications of ABA as a result [17]. Changing the format and delivery of the ABA parent training is often necessary to achieve participation [18], and acceptability of interventions is a key critical step in ensuring that they are both appropriate and, ultimately, implemented by families.

Cultural, as well as linguistic adaptation of evidence-based interventions are needed in order to increase acceptability with non-English speaking populations [15,18-22]. For example, adaptations for Latinx parents have been shown to improve recruitment and retention [15,18], increase parent satisfaction and lower parental stress [23], improve parenting practices and reduce children's challenging behaviors [15] and increase engagement [13]. Unfortunately, Board Certified Behavior Analysts (BCBAs) have reported feeling unprepared to work with diverse populations [24]. Metanlyses indicate that targeting interventions to a specific cultural group versus attempting to provide interventions to individuals from multiple cultural backgrounds is four times more effective [25]. Given these findings, the current study used a modification of an existing evidence-based program [7] to examine the feasibility and acceptability of that 10-week parent training program in Spanish, for Spanish-speaking parents of school-aged children with ASD. Specifically, this study looked at

a) The degree to which Spanish-speaking families found the recommended ABA interventions acceptable and useful to address a self-nominated behavior of their child.

b) Explore the effectiveness of the intervention on both child behavior and parent stress, if the interventions were implemented.

Methods

Participants

Spanish-speaking families were recruited via a posted flyer at a community therapy clinic providing speech, physical therapy, and occupational therapy for low-income families in Phoenix, AZ. The clinic served approximately 3,500 families per month across therapy types, with 85% of families speaking Spanish as their primary language. Almost all (90%) of families attending the clinic qualified as “low income” for services, and 70% of the clinic population had a formal diagnosis of ASD. Sixteen families were screened for participation. All children were evaluated at baseline to confirm an ASD diagnosis according to DSM-V criteria, using the ADOS-II [26] and the Vineland Adaptive Behavior Scales-2 [27]. Based on these assessments, nine families were found to meet all inclusion criteria (a child with a confirmed diagnosis of ASD, between the ages of 6 and 10 years old, with at least one parent able to attend parent training sessions). Eleven parents in nine families participated with voluntary informed consent. All of the parents were Latinx and 81.8% were mothers, with a mean age of 37.22 years (SD=4.55, range 30-42). Families’ incomes were an average of $35, 9429 (range $22,471-$79,000). The children
were predominantly male (77.8%), which is representative of ASD diagnosis rates within the general population. The children were an average of 7.2 years old (SD=0.67), and in grades K-3 (M=1st grade).

Study Design

This 10-week intervention feasibility and acceptability study used a convenience sample of Spanish-speaking families at one community clinic that completed measures on their child’s behavior and parental stress before and after the intervention, as well as tracking changes in child behavior and skill development during the intervention.

Intervention

An established parent-training in ABA [7] was adapted for monolingual Spanish-speaking families. All information and materials were delivered in Spanish, and were translated and checked by native Spanish-speakers for clarity and meaning. Childcare and food were provided for all sessions, and groups were held in the evening, after work hours. All sessions were conducted at the clinic where their child already received therapy services and transportation vouchers were available for any families needing transportation assistance. An initial assessment interview was conducted by the group leader, creating an opportunity to set expectations for intervention activities, and children were assessed by an independent evaluator to confirm diagnosis, and gather information on intellectual and adaptive functioning.

Parents participated in six, weekly two-hour long group sessions that were both didactic and interactive (power point presentation with videos, case studies and group discussion), with many examples used from the families’ daily lives to make the principles of behavior change relevant to parents. All sessions were conducted in Spanish with one main group leader and two assistants. Each session covered a new topic with some overlap to ensure comprehension from earlier sessions. The following topics were covered: the foundations of ABA interventions, defining antecedent triggers and consequences of existing problem behaviors, identifying the function of problem behaviors, and monitoring behaviors over time.

After six group meetings, parents then received four individual sessions with one of the group leaders. Parents identified one specific target behavior to teach or change, and developed an intervention plan and data collection to track progress. Parents tracked data on their own implementation of the intervention, as well as their children’s behavior each week and brought it back to the sessions to discuss and adjust the intervention (as needed) with the interventionist.

Measures

As noted above, Children completed the Autism Diagnostic Observation Schedule-II [27] and parents completed the Vineland Adaptive Behavior Scales-2 [27] at baseline to confirm a diagnosis of ASD, and assess functional behavior. In addition, children completed the Kaufman Brief Intelligence Test-2 [28] to get an index of intellectual functioning. These measures are all standards within the field with high reliability and validity to confirm diagnosis and functional levels.

Parents completed the Aberrant Behavior Checklist – Community [29], in Spanish, before and after intervention. This measure looked at child behavior problems within the community setting, and has five sub-domains, including: Irritability, Lethargy, Stereotypy, Hyperactivity, and Inappropriate Speech. The reliability and validity of the measure has been confirmed in multiple previous studies with varying special populations [30].

Parents also completed the Parent Stress Index-4th Edition Short Form [31] pre- and post-intervention. The PSI-4SF was administered in Spanish, and includes three calculated sub-domains of Parent Distress, Parent-Child Dysfunctional Interactions, Difficult child, as well as a global total stress index. The PSI-4SF has been shown to be a valid and reliable measure of parenting stress with low income, predominantly Hispanic parents [32].

Finally, throughout the intervention, parents collected Antecedent-Behavior-Consequence [33] data on the identified target behavior of their child. This ABC recording provided ongoing progress monitoring on improvements (or worsening) of the targeted behavior within the home or community. Parents brought these data in to each session to review with the interventionist and make any changes to the intervention that might improve ongoing progress.

Results

All children met criteria for ASD on the ADOS-II, and IQ scores averaged 63.67 (SD=18.68, Range = 44-97). Overall attendance in all sessions was high, at 84.46% across both group and individual sessions. Only one family did not complete the study, as they had trouble identifying a specific target behavior to use for intervention. Another family attended all group sessions, and the first individual session, but did not return, as they did not agree with the proposed intervention for their child.

As can be seen in Table 1, seven (77.8%) of the nine families reported that the recommended ABA intervention was acceptable and implemented it, as designed. All of these families saw improvements in the child’s targeted behavior as a result of intervention. Targeted behaviors ranged from non-compliance to
repeated screaming and crying, and were identified by parents as the most urgent behavior of concern at the time. Interventions were all ABA based strategies and were taught and practiced with families along with how to collect data and track their child’s behavior progress.

<table>
<thead>
<tr>
<th>Target Behavior</th>
<th>Intervention Plan</th>
<th>Change in Child’s Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-compliance</td>
<td>Reward System</td>
<td>Yes</td>
</tr>
<tr>
<td>Toilet</td>
<td>Toilet training with reinforcement</td>
<td>Yes</td>
</tr>
<tr>
<td>Crying for 2-5 hours nightly</td>
<td>Extinction</td>
<td>No, Parents did not implement intervention</td>
</tr>
<tr>
<td>Manding</td>
<td>Require and Reinforce manding</td>
<td>Yes</td>
</tr>
<tr>
<td>Pulling hair</td>
<td>Practice Opportunities-DRO</td>
<td>Yes</td>
</tr>
<tr>
<td>Screaming at school</td>
<td>Reward System</td>
<td>Yes</td>
</tr>
<tr>
<td>Inability to accept “no” (n=2)</td>
<td>Practice “no” with reinforcement</td>
<td>Yes (both improved)</td>
</tr>
<tr>
<td>No behavior identified</td>
<td>N/A</td>
<td>Parent did not attend individual sessions</td>
</tr>
</tbody>
</table>

**Table 1:** Target behaviors and interventions for participating families.

The Aberrant Behavior Checklist (see Table 2) was administered to parents at baseline and at treatment termination. There are five categories rated, including irritability, lethargy, stereotypy, hyperactivity, and inappropriate speech. Each of these areas were rated as improved from baseline to post-intervention (lower ratings of problem behavior at the end of the intervention), however, none of the changes were significant.

Parental stress (see Table 2) was also measured at baseline and again at treatment termination. Parents reported on parental distress, parent-child dysfunctional interactions, and their feelings of difficulty in interacting with their child. From these component scores, a combination score was calculated on total stress across areas. Parents showed significant reductions in parental distress (p=0.007), as well as total stress (p=0.045) as a result of the intervention, with ratings of difficult child behavior close to significant (p=0.055).

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-Intervention (n=7)</th>
<th>Post-Intervention (n=7)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aberrant Behavior Checklist</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irritability</td>
<td>17.50 (9.29)</td>
<td>10.25 (5.44)</td>
<td>p = 0.299</td>
</tr>
<tr>
<td>Lethargy</td>
<td>15.33 (6.03)</td>
<td>9.33 (3.06)</td>
<td>p = 0.332</td>
</tr>
<tr>
<td>Stereotypy</td>
<td>4.00 (3.41)</td>
<td>4.00 (2.61)</td>
<td>p = 1.000</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>22.33 (5.69)</td>
<td>12.67 (7.37)</td>
<td>p = 0.328</td>
</tr>
<tr>
<td>Inappropriate Speech</td>
<td>3.33 (2.58)</td>
<td>3.00 (2.28)</td>
<td>p = 0.805</td>
</tr>
<tr>
<td><strong>Parent Stress Index</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental Distress</td>
<td>63.29%</td>
<td>40.57%</td>
<td>p = 0.007</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional Interactions</td>
<td>72.00%</td>
<td>70.86%</td>
<td>p = 0.924</td>
</tr>
<tr>
<td>Difficult Child</td>
<td>72.41%</td>
<td>58.57%</td>
<td>p = 0.055</td>
</tr>
<tr>
<td>Total Stress</td>
<td>74.00%</td>
<td>56.57%</td>
<td>p = 0.045</td>
</tr>
</tbody>
</table>

**Table 2:** Aberrant Behavior Checklist and Parent Stress Index Pre- to Post-Intervention.
Discussion

This study examined the feasibility and acceptability of a parent training intervention teaching ABA strategies, in Spanish, for families with autistic children. Overall, the intervention was effective at helping families learn about and implement ABA strategies within the home, reduced parental stress, and almost all parent-nominated target behaviors (77.8%) improved over time. For all families who implemented a strategy with their child, there were clear observed improvements. However, acceptability of the proposed intervention was needed to ensure implementation.

Parent training on ABA in Spanish was feasible. Families attended the majority of both group and individual sessions. Parents engaged with the interventionist and one another during group sessions, and reported feeling that the intervention helped them to address behaviors of concern with their child. Family lives can be chaotic, and it is important to empower parents to be able to set goals and priorities and address the behaviors of most concern to them and their family. The intervention was translated into Spanish, but also adapted to include more videos and examples of each ABA strategy that was discussed. Opportunities were also presented to discuss each strategy and how it had been or could be used by participants.

The ABA strategies that the parents used within this study were effective at reducing the problem behaviors of their child, but not all suggested intervention strategies were deemed acceptable to all families. One family did not return to individual sessions after extinction was suggested as an intervention strategy for their child crying for over two hours per night. After some initial data collection, it was determined that attention was the function of this crying (the child was held and given lots of attention when it happened), and this maintained the behavior over months at the same time each evening. When extinction was recommended (removing attention when he cried at night), the family did not feel comfortable with this method. They felt it was too harsh and not in line with their parenting style. This has been seen in similar research with Chinese parents of children with ASD, where using positive reinforcement and strategies were rated as most acceptable [34]. This highlights the need to adapt strategies to use those with both the most efficacy for the function of the behavior, as well as the contextual (cultural and personal) needs and ideas of those implementing them. Those families (7/9) that did feel that the strategy fit with their parenting style were very effective implementers and saw significant improvements in the targeted behavior of their child.

Cultural, linguistic, and logistical adaptations need to be made to existing parent training interventions as they have predominantly been evaluated only with white, middle-class populations. Previous studies have used both language translation [21] as well as employing additional visuals [18] successfully, which were both employed in this intervention. In addition, logistic accommodations, such as holding sessions at the clinic where the child already received therapy services, and in the evening after work hours were used to help increase retention. Families were also provided food and childcare during sessions (for both the target child with ASD, as well as siblings), and transportation vouchers to attend the session, if needed. These accommodations were consistent with previous studies [13,15,22] and likely improved the retention rate of participants (over 84% of sessions attended), as well as allowing group sessions to be more informal, where people were meeting and learning over a shared meal. All accommodations were made while retaining all content from the evidence-based parent training curriculum [7], as it has been shown from previous studies that the most important component of cultural adaptions is to not interfere with the dose or exposure to content [15].

Although these results are encouraging in adapting existing parent training interventions for families speaking Spanish, this was a small sample of families (n=9) which needs to be tested with a larger diverse sample of families. It would also be ideal to include measures within the home that might better track parent implementation and child behavior change as a result of parent strategy use.

Overall, the feasibility and acceptability of this parent training intervention were high, along with the efficacy of the suggested strategies at changing child behavior. This suggests that parent training in ABA strategies in Spanish can be a useful avenue to address child behavior within the home and community. The more we can adapt parent interventions to make them accessible and acceptable to all populations, the more foundational support can be delivered to children with ASD within all communities.

Declaration of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References


