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Feasibiltiy and acceptability of Spanish-language parenting interventions for young children with developmental delays --Manuscript Draft--

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January 9, 2023

Dr. Susan B. Palmer,

Associate Editor, Intellectual and Developmental Disabilities

RE: Manuscript IDD-D-22-00019

Dear Dr. Palmer,

Thank you for your interest in a revision of our paper to *Intellectual and Developmental Disabilities* "Feasibility and acceptability of Spanish-language parenting intervention for young children with developmental delays" (IDD-D-22-00019). We have made the three changes in APA style that you suggested: 1) removing the word count from the abstract, 2) putting the title rather than "introduction" as the initial header, 3) subsuming the Data Analysis section into the Method section.

Thank you for your consideration. We look forward to hearing from you.

SPANISH LANGUAGE PARENTING INTERVENTIONS

Feasibility and acceptability of Spanish-language parenting

interventions for young children with developmental delays

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Abstract

Hispanic/Latinx parents of children with developmental delays/disabilities (DD) face disparities in service access and research participation. In the present study, 60 Spanish-speaking caregivers of young children with DD participated in randomly assigned stress reduction interventions (psychoeducation/support groups or Mindfulness-Based Stress Reduction [MBSR]), followed by behavioral parent training (BPT). Caregiver attendance and satisfaction ratings were measured, and focus groups gathered additional information on caregivers' takeaways from the interventions. Caregivers demonstrated high satisfaction across interventions, with slightly greater preference for psychoeducation/support groups, and qualitative data indicated that the relevance of the information and style of delivery may be responsible. Researchers and clinicians may attain greater engagement with this population by focusing on intervention services that include psychoeducation and peer support elements.

Key words: developmental delay, Spanish, Hispanic/Latinx, stress reduction, behavioral parent training

Feasibility and acceptability of Spanish-language parenting interventions for young children with developmental delays

Hispanic/Latinx¹ individuals represent the fastest growing population diagnosed with autism and other developmental delays/disabilities (DD) in the United States (Maenner et al., 2020). As such, there is an increasing need to identify and provide appropriate intervention services for Hispanic youth with DDs and their caregivers. Unfortunately, research suggests that existing service systems often fail to meet the treatment needs of Hispanics with developmental disabilities (Nguyen et al., 2016). Spanish-speaking families experience additional challenges including fewer intervention hours and more unmet intervention needs, with some studies showing English-language proficiency to be the single most important factor in predicting access to services (Zuckerman et al., 2017). Culturally diverse families have also been underrepresented in DD treatment research (e.g., Safer-Lichtenstein et al., 2019; West et al., 2016). This underrepresentation in the literature has been attributed to cultural differences in familiarity with research, socioeconomic and language barriers, and a lack of targeted efforts to engage this population (Ratto et al., 2017). One way that such disparities can be attenuated is through research to test whether widely utilized, evidence-based, DD intervention practices are feasible and acceptable when delivered in Spanish.

Interventions that support caregivers who are parenting children with DD are needed given heightened psychological distress associated with parenting a child with a disability (Baker et al., 2003). Two interventions that target stress reduction and positive coping are Mindfulness-Based Stress Reduction (MBSR; Dykens et al., 2014; Neece et al., 2014) and psychoeducation/support groups (Bitsika & Sharpley, 2000). MBSR is an intervention that utilizes a combination of mindfulness meditation, body awareness, and exploration of thoughts and actions, and has numerous studies providing empirical support of stress reduction benefits (see Grossman et al., 2004, for a meta-analysis). There is also a growing body of research that MBSR interventions may be particularly beneficial for caregivers of children with autism and DD (Dykens et al., 2014; Neece et al., 2014), and that it can be effective with

¹ The term Hispanic is used throughout the remainder of this manuscript as it is the preferred term of the majority of members of this community (Noe-Bustamante et al., 2020).

Hispanics (Castellanos et al., 2020; Neece et al., 2019). Psychoeducation groups teach caregivers broad knowledge-based content (i.e., about disabilities and how to attain services), and is often combined with support group elements, such as sharing of common experiences between caregivers (Steiner et al., 2012). Psychoeducation groups may have some impact on caregiver stress (e.g. Cappe et al., 2021), but this has not been studied extensively nor is it the focus of such programs. To date, one psychoeducation program has been developed for Hispanic caregivers of children with autism. This program, called Parents Taking Action, piloted a health navigator model of service delivery (Magaña et al., 2017), and demonstrated improvements in caregiver knowledge of rights, but not mental health (Lopez et al., 2019).

Additionally, children with DD average three to four times the number of behavioral challenges as their typically developing peers (e.g., Baker et al., 2003). Given that child challenging behavior is a frequent concern of caregivers of children with DD (Matson & Nebel-Schwalm, 2007), interventions targeting the reduction of behavior problems in children with DD are common. An intervention that is considered cost-effective and easy-to-implement is Behavioral Parent Training (BPT) modified to meet the needs of children with DD (McIntyre, 2013). Furthermore, research indicates that Hispanic caregivers may benefit similarly from BPT as non-Hispanic White caregivers (Ramos et al., 2018). Calzada and colleagues (2013) conducted focus groups with Hispanic mothers around BPT and found that they viewed some strategies acceptable, including specifically the use of praise and social rewards, while finding other strategies (i.e., elimination of spanking) less acceptable, and being divided on others (i.e., time-out).

Despite general acceptability of BPT strategies, there remain challenges for researchers in getting families to consistently attend and engage in such sessions. Thus, there is also a need to test the most cost-effective and feasible manner for delivering these types of interventions, with growing evidence supporting telehealth (Corralejo & Rodriguez, 2018). In order to begin developing the evidence base for treatments with this population, an important first step is to examine acceptability and feasibility of intervention content, study design, and procedures (Gadke et al., 2021). Establishing initial acceptability and feasibility through investigating attendance, satisfaction, and alignment with cultural and familial values and norms, is essential to informing the next steps of this program of research. Once preliminary

evidence of acceptability and feasibility is established, efficacy of intervention on child and caregiver outcomes can be investigated. Prior studies have indicated a link specifically between caregiver acceptability of intervention and child outcomes (e.g. Rothschild et al., 2021). In the present study, the feasibility and acceptability of psychoeducation, MBSR, and BPT interventions, as well as telehealth delivery modality, are investigated with Spanish-speaking Hispanic caregivers of children with DD. The data gathered from this process can address the dearth of studies examining parenting interventions for Spanish-speaking caregivers of young children with DD and inform the field about the types of interventions that can be feasibly delivered with this often underserved population.

Literature gap and research questions

While the aforementioned interventions (psychoeducation, MBSR, BPT) have been shown to be generally effective with White middle- to upper-socioeconomic status (SES) families, there is much less evidence of their effectiveness when delivered in Spanish to lower- SES Hispanic caregivers of children with DD. Furthermore, limited studies have looked at the effectiveness of using telehealth intervention with these families. Questions of feasibility and acceptability are especially relevant among these groups given the relative dearth of research on interventions delivered in Spanish. Specifically, we sought to examine: 1) at what rate would caregivers attend intervention groups and would there be any differences between those who participated in BPT-E and BPT-M?; and 2) how acceptable and feasible would caregivers find the interventions and would there be any group differences in acceptability or attendance?

Method

Study Design

The present study is part of a larger NIH-funded longitudinal, randomized control trial (RCT) examining differences between two interventions aimed at helping caregivers of young children with DD cope with stress and manage child challenging behavior (GRANT INFORMATION REDACTED). This RCT is ongoing and is being conducted in LOCATIONS REDACTED. The two interventions being compared in the larger RCT are BPT combined with MBSR (BPT-M) and BPT combined with psychoeducation/support (BPT-E). In this trial, participants are enrolled and randomized to either the

BPT-M or BPT-E condition and receive their intervention in a group-delivered format. In BPT-M, participants received six weeks of group-based MBSR intervention, followed by 10 weeks of BPT. The MBSR intervention consisted of didactic training, practice exercises, and discussions about mindfulness. In BPT-E, participants received six weeks of group-based psychoeducation, again followed by 10 weeks of the same BPT intervention. The psychoeducation intervention was designed as a support group in which caregivers were provided with information and encouraged to discuss relevant supports and resources for their child related to their development, disability, education, therapies, and other services.

The core 10 week BPT intervention for both groups was an adaptation of the Incredible Years Parent Training (IYPT) program for children with DD (McIntyre, 2008a; 2008b). This manualized intervention incorporates elements of standard BPT (i.e., positive parenting, praise, and rewards), with some modifications, such as removing content around "time out" that has proven less effective for children with DD, and adding additional content on predicting and responding to challenging behaviors. Although BPT is delivered to participants in both conditions, caregivers remain in their original group assignment. The reason for this treatment order in the larger RCT is to test the additive effects of a stress reduction component prior to BPT, with MBSR directly targeting stress and psychoeducation serving as an active control. Also of note, the content of all three of the above programs was directly translated to Spanish but was not further adapted or modified. Video examples that accompany the BPT curriculum were provided dubbed in Spanish by the IYPT publishing company (Webster-Stratton, 2013). While the larger RCT also includes several English-speaking cohorts across sites, efficacy data across cohorts will not be disseminated until the trial is complete. The present study focused on feasibility and acceptability of the interventions for the monolingual Spanish-speaking cohort (N = 60) in REDACTED. These groups were delivered entirely in Spanish, consistent with caregiver input that this would be of greater benefit than interventions delivered in English with live interpreters (Neece et al., 2019). Furthermore, due to the unfortunate circumstances brought on by COVID-19, intervention groups for Spanish-speaking caregivers of children with DD were delivered via telehealth for the first time (McIntyre et al., 2021).

Participants

Primary caregivers of preschool-aged children (3-5 years) were recruited to participate in this study. To be eligible, children needed to have either a medical diagnosis or early childhood special education eligibility of autism or DD, and to experience elevated behavior problems based on two screener questions (i.e., my child has behavior problems frequently and my child's behavior problems are intense in nature) on which parents had to answer somewhat true or very true. Caregivers were excluded from study participation if (a) they screened positive for active psychosis, substance abuse, or suicidality; (b) they were currently receiving any form of psychological or behavioral treatment at the time of referral (e.g., counseling, caregiver training, caregiver support group); or (c) their child had significant sensory impairments (e.g., deafness, blindness) or nonambulatory conditions that would necessitate the need for significant modifications to the study protocol. For the Spanish-speaking cohort, all caregivers were Hispanic who identified Spanish as their primary and/or only language.

Recruitment took place through the distribution of informational flyers to regional service centers in the greater REDACTED. Potential participants were invited to contact the project office to express their interest in participating, and these caregivers were then contacted by a bilingual research assistant. In total, 207 Spanish-speaking caregivers expressed initial interest in this study and 60 were enrolled. See Figure 1 for additional recruitment details. Randomization occurred at baseline (described below).

Procedure

Eligible participants were assessed at baseline in an initial home visit where informed consent and demographic information were gathered. All measures were administered in Spanish by bilingual research assistants. Participants were then randomly assigned to either BPT-M or BPT-E, and completed a brief motivational interview designed to improve parent engagement in the interventions used in the study. The motivational interview was designed to elicit self-motivational statements from participants about their desire to participate and their goals and hopes for the intervention, as well as address potential barriers to engagement (Nock & Kazdin, 2005). Enrolled participants were also contacted by study staff the week before the intervention to be reminded about the upcoming groups and their goals for the intervention.

Intervention groups were run concurrently (i.e., BPT-E on Monday and BPT-M on Wednesdays)

over the course of the 16 weeks. Each session was scheduled for two hours, and was intended to be run in-person at REDACTED University. As recommended by Ratto et al. (2017), sessions were run in the evening so that caregivers were able to attend around their work schedules, snacks and childcare were provided, and research staff communicated with families via text to check-in and provide reminders about group each week. After week six of the intervention, coincidentally falling immediately after caregivers had completed the stress-reduction interventions (MBSR or psychoeducation), groups were paused due to COVID-19 school closures and restrictions on public gatherings. Following a four-week pause, groups resumed with the BPT curriculum delivered in a synchronous, live telehealth format delivered via a HIPAA-protected and licensed Zoom platform. Prior to resuming the groups online, participants were surveyed by study staff about their willingness and technological capability to access groups in this manner, with the vast majority responding positively to this potential change (McIntyre et al., 2021).

Focus Groups

Participants in the Spanish cohort were invited to participate in focus groups approximately five months after completion of the interventions, to gather additional, qualitative, information about how acceptable and relevant caregivers found the intervention groups. Given the aforementioned dearth of research with this population, this mixed method design highlighted by the focus groups was critical to expand upon participant reactions to specific elements of the interventions to inform future work with this population. Focus groups were conducted five months after the intervention so that they did not overlap or introduce unnecessary bias into the post-intervention and long-term follow-up assessments that were conducted as part of the larger RCT. Further, we wanted to determine what intervention strategies were still being used by caregivers several months after the intervention ended. A total of four focus groups were run over Zoom with two time options each for those who took part in BPT-E and BPT-M respectively. In order to be eligible to participate in the focus groups, participants needed to have attended at least one session of the first six weeks of intervention (MBSR or psychoeducation) and one session of the final 10 weeks of intervention (BPT), in order to have at least some knowledge of the content of the groups from which to base opinions. All 38 participants who met this qualification were invited.

A total of 24 caregivers participated in the four focus groups (14 across the two BPT-E focus groups; and 10 across the two BPT-M focus groups). These 24 participants had attended an average of 5.46 of the six initial psychoeducation or MBSR sessions, and an average of 8.29 of the 10 BPT sessions. Each group met for 1.5 hours and was facilitated by the first author and another research assistant. Focus groups utilized a semi-structured format to make sure specific areas were covered adequately at each group, but participants were encouraged to discuss and expand upon topics as they wished. All focus groups began with the facilitator briefly reviewing the content of the interventions they had participated in (i.e., psychoeducation and BPT or MBSR and BPT). The remaining time of the focus groups was divided into three sections: 1) aspects of the interventions participants found most relevant and helpful to continue using five months later; 2) aspects of the interventions they did not like or had not been able to continue using, and barriers to implementing strategies; and 3) generally how well they felt the interventions were aligned with their individual/ familial/ cultural values, whether they thought other Hispanic families would find the strategies feasible and acceptable, and how the content could potentially be adapted to be more relevant to Hispanic families. Caregivers were compensated \$25 for participating in the focus group.

Measures

Demographics

During the baseline assessment, all participants completed a demographic intake form with information such as caregiver and child age, biological sex, race and ethnic background, language spoken at home, highest level of caregiver educational attainment, household income, and child diagnosis.

Caregiver education level was dichotomized as above or below high school graduate, as that represents a base level of education often needed for employment and other opportunities in the United States. Income was dichotomized as above or below \$30,000 because it roughly represents the federal poverty threshold for a family of four or five in the years the data were collected. Finally, caregivers reported on their service utilization, including any outside services the caregiver or child was currently accessing.

Attendance

The number of sessions attended by each participant was averaged to create a mean attendance

score for each of the two intervention groups. See Figure 2 for attendance in the Spanish cohort by group.

Acceptability

The acceptability, or social validity, of the intervention groups was measured at the end of the intervention phase (post-treatment) using the Parent Satisfaction Questionnaire, an adapted version of the Consumer Satisfaction Questionnaire (Forehand & McMahon, 1981). This measure has been adapted and utilized in numerous previous trials investigating versions of IYPT (i.e., Webster-Stratton, 1994; McIntyre, 2008a). Caregivers completed this measure based on the acceptability of the group leader, group dynamics, video vignettes, strategies taught to reduce stress, and strategies taught to manage child challenging behavior. Caregiver responses on 15 seven-point Likert scale items are summed to create an Overall Satisfaction score between 15 and 105, with higher scores indicating greater acceptability (Reid et al., 2001). This tool has previously demonstrated adequate psychometric properties (McIntyre, 2008a). The measure was collected during the final session, or week 16. Only about half of participants attended the week 16 session (n = 28), and thus we only have acceptability data from these caregivers.

Acculturation

The Vancouver Index of Acculturation (VIA; Ryder et al., 2000), a 20-item scale measuring two domains: orientations towards heritage and towards mainstream cultural groups, was used to assess acculturation in the study sample. Two separate scores are generated (Heritage Subscore and Mainstream Subscore), with higher score indicating a positive orientation toward the specific cultural group. Internal consistency reliability for the VIA in the present sample was Chronbach's $\alpha = .88$ for the Heritage Subscore and Chronbach's $\alpha = .90$ for the Mainstream Subscore, indicating that there was high internal consistency. Unsurprisingly, VIA acculturation mainstream and heritage subscores were highly positively correlated with each other (r = .41, p < .001.). We decided to examine VIA mainstream subscores, as those are likely to more accurately represent willingness to buy-in and engage with an intervention delivered in the mainstream culture, as was the one used in the present study.

Parenting Stress

The Parenting Stress Index, Fourth Edition- Short Form (PSI-4-SF; Abidin, 2012) Total Parenting

Stress score was used to measure to stress in the current sample. Internal consistency for the PSI in the present sample was high, with Chronbach's $\alpha = .88$.

Child Problem Behaviors

Child problem behaviors were measured in this study utilizing caregiver report on the Child Behavior Checklist for children 1.5 to 5 years old (CBCL; Achenbach & Rescorla, 2000), Total Problems score. Internal consistency reliability for the CBCL in the present sample was Chronbach's $\alpha = .95$ for the Total Problem Behaviors score, indicating that there was very high internal consistency.

Data Analysis

Quantitative Data

Descriptive analyses were run for variables of interest, including acceptability, key demographics, caregiver stress, acculturation, and child challenging behaviors. Those who had completed the Parent Satisfaction Questionnaire were compared with those who had not, examining differences in key demographics, including caregiver educational attainment and family income, caregiving stress, acculturation, and child challenging behavior. These groups were compared using chi-square tests for categorical variables (i.e., educational attainment and household income) and independent samples *t*-tests for continuous variables (i.e., caregiver stress, acculturation, and child challenging behavior).

To address the research questions, descriptive analyses were run on attendance and acceptability separately for the cohort overall, and independent samples *t*-tests were run using intervention group as the independent variable, with satisfaction and then attendance as dependent variables.

Qualitative Data

All focus group recordings were transcribed verbatim and anonymized. We used thematic analysis (Braun & Clarke, 2006) to analyze the data. As part of this process, data were initially coded separately by two bilingual graduate students (first and fourth authors) with supervision and input from a doctoral level qualitative methodologist (fifth author). During this phase, data were coded and initial discursive themes were identified. Coding involved reading through the data and re-watching the focus groups multiple times, then developing a set of broad descriptive codes based on the protocols. Code

examples included: "inconsistent use," "sense of community," "cultural alignment," etc. Coders then met together to reach consensus on these codes and to identify and interpret some of the broader themes into which these codes could be grouped. The two coders identified very similar themes, and in the few instances of disagreement, differences were discussed to arrive at consensus. Codes were first collapsed within each intervention group (i.e., to establish a set of codes for BPT-E and BPT-M groups respectively), regardless of which focus group they attended. These codes were then compared against each other to identify which codes were intervention-specific, and which could apply to the overall trial. Codes were similar across groups, ultimately resulting in five themes that held across both intervention groups, and one each that was specific to BPT-E and BPT-M interventions respectively.

Results

Quantitative Data

Individuals who completed the acceptability measure were compared with those who had not. For week 16 total program acceptability, there were no baseline differences between responders and non-responders on stress (PSI), challenging behavior (CBCL), acculturation (VIA mainstream) scores, intervention group, or education (p > .05). There were, however, statistically significant differences between responders and non-responders on income (p = .048), with lower-income participants being less likely to have completed the measure.

Overall, participants were well-matched across BPT-E and BPT-M conditions in this cohort, and there were no significant differences in demographic variables (see Table 1). Distribution of satisfaction scores and attendance were unimodal and approximately normal with no severe skew or outliers, and thus the use of parametric testing methods was appropriate. After week 16, ratings of satisfaction were high in both groups, with mean satisfaction scores of 95.21 and 90.31 (out of 105 maximum score) for those who participated in BPT-E and BPT-M respectively. These equate to average item scores of 6.35 and 6.02 respectively (on a 7-point Likert scale) across the 15 items that were used to measure overall intervention satisfaction. These differences approached, but did not reach, statistical significance, t(25) = 1.93, p = 0.065. We also ran analyses on intervention attendance. There were no significant differences between

BPT-E and BPT-M attendance for either the first six week, in-person, sessions, t(58) = 0.41, p = .684, or the latter 10 week, virtual BPT sessions, t(58) = -0.06, p = .951.

Qualitative Analysis

Our thematic analysis revealed that participants found many aspects of the interventions feasible and acceptable, while other aspects of the groups created greater challenges or barriers in either their relatability to families or sustainable use. Seven themes emerged from focus group discussions of intervention strategies, two of which seemed unique to their specific intervention, and five of which appeared to cut across intervention condition. The seven themes were: (1) BPT-M: feasibility challenges in continued use of MBSR strategies; (2) BPT-E: great satisfaction for discussions around school advocacy and their child's Individual Education Program (IEP); (3) Both conditions: found a lot of benefit learning from other caregivers and feeling less isolated, peer-to-peer, other caregivers as models; (4) Both conditions: generally satisfied with behavioral strategies (i.e., praise, rewards, focus on positive/ignoring negative behaviors, strategies for virtual school during COVID); (5) Both conditions: experienced feasibility successes and challenges in getting other family members on board; (6) Both conditions: found content other than video examples culturally acceptable; appreciated groups being delivered in Spanish; (7) Both conditions: mixed satisfaction on delivery modality of in-person versus via telehealth. Representative participant quotes for each theme have been provided in Table 2.

Theme 1: Inconsistent Use of MBSR Strategies

Participants in BPT-M reported rather differing opinions about the extent to which they found MBSR strategies, such as meditation, visualization, and breathing, to continue to be feasible in the five months following the completion of intervention. There were several caregivers who reported that they had been able to continue using MBSR strategies and found them helpful in both everyday life and in moments when they were feeling particularly stressed. In contrast, other caregivers described challenges they had with maintaining use of the MBSR practices beyond the intervention sessions. While even those caregivers who were not still using the MBSR strategies reported finding benefit in them at the time of the

groups, they detailed several logistical barriers to the ongoing practice, including having trouble finding the time/space to do it, and struggling to engage in meditation without the group leader to guide them.

Theme 2: Satisfaction with Psychoeducation

Participants in BPT-E reported great benefit, including increased self-efficacy, from the discussions around school advocacy and developing their child's IEP. These participants detailed how their increased knowledge in these service systems increased their confidence in working with school teams and even changed some immediate outcomes for their children. Some of the caregivers of the caregivers in the BPT-E group were able provide very specific and timely examples of how they had used the information from the groups to feel confident protecting their rights in schools or other systems.

Theme 3: Satisfaction with Sense of Community

Participants in both intervention conditions reported learning a lot from the other caregivers in their group, and seeing the other caregivers as role models who they hoped to emulate with their own parenting practices. Participants also reported feeling less isolated as a result of the groups, and appreciated being able to meet and talk to other caregivers of children with developmental disabilities. Many of the caregivers felt that they learned specific techniques/strategies from the other participants in the group, and found it particularly useful to hear that things worked for those with similar lived experiences to themselves. The caregivers in both intervention conditions, although slightly more in the BPT-E group where this was an explicit focus of the first six weeks of intervention, also noted the importance of just knowing there were so many people near them with similar stories.

Theme 4: Feasibility of Behavioral Strategies

The majority of participants across both intervention conditions reported that the behavioral strategies learned during the final 10 weeks of intervention (BPT) were useful and that they continued to use them. The most commonly reported strategies that caregivers were using were praise and rewards systems. Other specific behavioral strategies that participants reported continuing to use following the interventions included understanding and intervening based on functions of behavior, following the child's lead during play, and having more patience/ giving fewer commands with their child.

Theme 5: Feasibility of Incorporating Other Family Members

Participants across groups reported successes and challenges integrating other family members into using the strategies. Although participants were allowed to bring one other caregiver with them to groups, many came by themselves and had to determine how and whether they would disseminate the information to their families. Several participants discussed benefits they had seen in being able to teach group strategies to other family members (e.g., spouses, grandparents, older children) who regularly took care of the child with DD. On the other hand, there were also participants who reported difficulties implementing strategies from the interventions because other family members who did not attend the groups did not understand or know how to use the same strategies. These participants suggested that it may be beneficial in future iterations of these interventions to make a more conscious effort to invite and encourage other family members to attend sessions, rather than just one primary caregiver.

Theme 6: Cultural Acceptability

Participants in both groups generally found the content culturally acceptable, and appreciated having groups in Spanish. Participants did not feel that group strategies had any culturally specific leanings toward them, and appreciated what they saw as 'neutrality' in how different ideas were presented. Others also noted that it would be unfair to group all Hispanic parents under one umbrella set of beliefs, particularly since multiple nationalities were represented. Many participants noted that having the groups delivered in their native language of Spanish was particularly meaningful, and hoped that such opportunities would continue for other Hispanic caregivers. Video examples that came as part of the IYPT curriculum were the only element reported to be inappropriate, both in terms of culture and content. These videos were over 20 years old, featured predominantly children without disabilities, and included mostly White families (dubbed in Spanish), leaving some participants struggling to relate to the videos.

Theme 7: Satisfaction with Delivery Modalities

Participants across groups had mixed feelings with regard to intervention delivery modality of inperson versus via telehealth. Although the program was never intended to be delivered remotely, all of the BPT intervention for both groups was delivered as such due to COVID-19. The most commonly endorsed advantages of in-person delivery were the ability to meet people in person and establish better connections, and because the in-person groups provided childcare to take that burden away from caregivers during sessions. In general, the caregivers who preferred the telehealth delivery noted the convenience of being in one's own home and not having to travel to the university to receive services. As noted in the methods section, participants were traveling from an average of 25.1 miles away, and required significant time commitment for those coming from further away.

Discussion

A series of evidence-based parenting interventions were delivered in Spanish to Hispanic caregivers of children with DD, the group least often included in intervention studies (West et al., 2016). With consideration of our first research question, despite the uncertainty of both running such interventions for the first time, and the impact of the COVID-19 pandemic (Neece et al., 2020), Spanish-speaking participants engaged in the interventions with attendance rates comparable to those found in the literature for BPT interventions (Chacko et al., 2016). This was consistent with the findings of Ogg and colleagues (2014) and McCabe and Yeh (2009), that caregiver training groups could draw comparable attendance in Spanish. There were no major differences in our study in attendance between the BPT-E and BPT-M groups, indicating either type of intervention could result in similar engagement.

In examining our second research question on intervention acceptability, as measured by participant satisfaction ratings, there was a slight preference for BPT-E over BPT-M, perhaps indicating the importance of psychoeducation for this population. Qualitative data gathered from the focus groups also corroborated these findings. Participants in the Spanish language BPT-E group reported that they felt increased parenting self-efficacy and knowledge of their parental rights stemming from implementing the information they had learned in this group, consistent with the existing literature on psychoeducation groups with this population (Lopez et al., 2019; Magaña et al., 2017). These findings indicate the importance of providing underserved caregiver groups, such as Spanish-speaking Hispanics, the information to be able to feel confident in advocating for their child, as they may be less likely to gain that knowledge from other sources (Chlebowski et al., 2018). In terms of specific psychoeducation topics

that may be particularly valuable for this population, focus group participants repeatedly referenced the importance of being able to advocate in school via the IEP process. A literature review by Wolfe and Duran (2013) highlighted the complexities of the IEP process as being especially difficult for culturally and linguistically diverse families, in part due to insufficient information on how to become involved and advocate. Therefore, it makes sense that school advocacy would be a highly desired, and often overlooked, area of knowledge for these families.

Focus group data indicated MBSR practices may have been slightly more challenging, as participants in this study were mixed in the degree to which they continued to use MBSR strategies several months after the intervention, with multiple caregivers expressing they did not have time in their daily lives to carve out for such self-care activities, or were not able to do the activities without the group leader to guide them. Although it is unclear if the barriers to implementing MBSR practice were related to the impact the COVID-19 pandemic had on family daily life, future iterations of MBSR for this population could be enhanced. For example, more information about the importance of establishing a self-care routine could be added, as well as building in more scaffolded practice opportunities so caregivers could feel more comfortable using the strategies at home without the group leader present.

Participants in both intervention groups reported appreciating and benefitting from meeting other caregivers with similar stories to their own (i.e., other Spanish-speaking Hispanic caregivers of a child with a disability), learning what strategies others had found effective, and viewing fellow participants as role models from which to base their own parenting behaviors and attitudes. Taken together, these principles can be viewed under the common umbrella of learning through community or collective experience, referred to in the literature as *convivencia*. While the term *convivencia* does not translate directly to any one word in English, Jasis and Ordonez-Jasis (2004) define it as "the flowing moments of collective creation and solidarity, the bonding that developed from a joint, emerging moral quest against the backdrop of experiential learning" (p. 35). This process of coming together as a group to learn from one another speaks to the importance of group-based interventions for Spanish-speaking populations. It also highlights the value of allowing participants to share their own stories and experiences as part of the

intervention process, rather than simply treating an intervention as passing along information.

Overall, behavioral strategies were rated favorably in both the quantitative satisfaction ratings and the focus group elaborations. This was generally aligned with the literature on how Hispanic caregivers view common, "evidence-based," parenting strategies. Consistent with the findings of Calzada and colleagues (2013), the majority of caregivers in the present study found the praise and rewards to be acceptable and beneficial. Strategies that mothers in the Calzada et al. (2013) study found less acceptable, such as using time-out and eliminating spanking, were not explicitly addressed as part of the adapted IYPT curriculum (McIntyre, 2008a) used in this trial. Our promising findings on the acceptability of BPT strategies with this population correspond with what prior studies have found. Although they utilized a different behaviorally-based parenting intervention, PCIT, separate studies by McCabe and Yeh (2009) and Ramos and colleagues (2018) both found Hispanic caregivers demonstrated high levels of satisfaction and buy-in with the strategies presented. DuBay and colleagues (2018) similarly found that Hispanic caregivers of children with autism considered the majority of behaviorally-based strategies acceptable.

Another important takeaway from the present study is around the importance of family, or familismo, in these interventions. Familismo, or strong bonds among the nuclear and extended family members, is a commonly identified value in Hispanic parenting literature (e.g., Ramos et al., 2018). Estrada and Deris (2014) found that Hispanic families with a child with autism relied on more members of the family than just the parents as caregivers, including grandparents, aunts/uncles, and older children. During the focus groups, participants reported both successes and challenges with incorporating other members of the family in using the strategies that they had learned during the groups. One caregiver suggested that future projects make it a greater priority to invite the whole family to participate. While the study did allow primary caregivers to bring one alternative caregiver with them to groups, this consideration of the importance of the whole family, and how to best get extended family members more involved, could be of significance for maximizing the effectiveness of these programs.

Additionally, although the current study did not make any explicit cultural adaptations beyond the direct translation of the interventions and program materials, the majority of participants reported that the

program was well aligned with their cultural and familial values. It is often assumed that interventions that have been primarily developed and utilized with one population (i.e., higher SES and White) inherently will not work as well with other groups (Parra Cardona et al., 2012). While there is evidence that parent training programs culturally adapted for ethnic minority caregivers are effective at improving parenting behavior (van Mourik et al., 2017), they may not necessarily be better than directly translated evidence-based interventions (McCabe & Yeh, 2009). As predicted, participants in the present study greatly appreciated being able to receive this intervention in their native, and felt the interventions had generally been appropriate despite no other tailoring. Some participants even noted that they appreciated that the content was not specifically culturally targeted to Hispanic populations. While intervention strategies have been developed primarily from one cultural lens, they may be more generalizable than believed. Participants did specifically note that video examples used in the intervention could be made to be more representative and relevant for Hispanic populations. This may point to a need to increase representation in examples, if not necessarily the need to completely overhaul content, to improve buy-in.

Finally, there remain a lot of unknowns with regard to delivery modality of interventions for this population. Participants had mixed reactions to the intervention delivery via telehealth, with several notable pros (i.e., not having to drive to intervention sessions, more comfortable at home) and cons (i.e., increased distractibility at home, lack of child care, difficulty with technology). Telehealth may reduce barriers to intervention access particularly for those living in more rural areas (Bearss et al., 2018). Participants in this cohort were traveling an average of 50 miles round trip, which likely added to the perceived benefits of telehealth for those individuals. Also of note is that the participants in the present trial did not originally sign up for treatment to be delivered remotely via telehealth, but were rather thrust into it as necessitated by COVID-19. Therefore, their opinions may differ from individuals who originally agree to be included in a telehealth study, and must be treated with caution. McIntyre et al. (2021) provides a deeper look into the adaptations that were made to move this intervention to telehealth, the technology support provided to participants, and the reactions of participants to these changes.

Limitations

There are several limitations to the present study, many of which relate to attendance/response rates of participants within the study. Attendance was less than desired with both intervention groups, averaging about 50% across the study, despite efforts to increase buy-in and engagement through motivational interviewing. Although approximately 50% attendance was below the goal for this study, it is within the range of typical attendance in BPT interventions in general, with a review finding BPT attendance to vary between 37% and 98% across studies for those who attend at least one session (Chacko et al., 2016). An additional limitation is that intervention satisfaction data were collected only from those who were in attendance at the final session, and thus we only have that data from 28 of the 60 (47%) participants to have completed the intervention. A power analysis indicated analyses were slightly underpowered for analyses involving satisfaction, which had fewer respondents, but were sufficient for the analyses of attendance. Overall, the sample size reflected the exploratory/pilot nature of the research.

We also did have slight income differences between those who completed the satisfaction survey and those who did not, which may impact generalization of these results. Similarly, with the focus groups, the participant pool was limited to those who attended a minimum of one session from the first six weeks and one session from the final 10 weeks. Thus, these data may not represent study participants at-large. Finally, the present study does not examine any intervention outcomes or effects, i.e. caregiver stress and child behavior, as these are aims of the larger NIH-funded grant (REDACTED), and thus will not be analyzed until all cohorts are completed. Despite these limitations, this study makes a valuable contribution by piloting several parenting interventions for the first time with Spanish-speaking caregivers of preschool-aged children with DD, thus laying the groundwork for critical future research.

Future Directions

The future directions of this study will involve completing analyses of key outcomes (caregiver stress, caregiving behavior, and child behavior), including comparisons between the Spanish and English cohorts. These data will be used in conjunction with the satisfaction and focus group results to further develop and adapt these interventions for this population. This study further illuminated the value that Spanish-speaking Hispanic caregivers of children with DD place on being able to meet and learn from

others like them, and thus this format should be retained in future iterations. Similarly, incorporating psychoeducation or knowledge of how best to advocate for the rights of their children may be of greater benefit for these families, and should continue to be interwoven within intervention work.

Additionally, future iterations of these interventions with this population should consider the use of greater cultural adaptation of program materials and strategies (Kuhn et al., 2020). Based on the high levels of satisfaction and positive feedback from those who participated in the present study, it is unclear whether the content of these interventions needs a total 'cultural adaptation.' One specific idea would be to incorporate video vignettes that are better tailored to the participants, include Hispanic caregivers and children with DD, and are set more recently. In their present forms, the interventions used in this study would be considered a surface level cultural adaptation, as they are matched to "superficial" characteristics of the target population such as names and languages (Resnicow et al., 1999). In order to achieve a deeper, structural, adaptation the interventions would need to more consciously target the values, beliefs, context, etc., of the population. This process involves developing, piloting, and receiving feedback on a surface level adaptation, which we have now done with the focus groups in the present study, and using that data to inform a later iteration that attempts deep structure adaptation. Furthermore, there are increasing calls in the field to directly test the effectiveness of surface level and deep level adaptations against one another (Ortiz & Del Vecchio, 2013). A critical future study could involve examining the additive benefits of a deep structure cultural adaptation of BPT-E and BPT-M compared to the surface level/ directly translated programs in both satisfaction and outcomes. This proposed study would greatly inform future directions for the field of culturally diverse DD research as a whole.

Conclusion

In sum, the present study adds data on the extent to which child behavioral and caregiver mental health services delivered in their preferred language are feasible and acceptable to an often underserved population of families of young children with DD. Findings suggest that Spanish-speaking Hispanic caregivers may prefer psychoeducation and peer supports over MBSR. Thus, the data gathered from this

study are an important first step for better understanding how to best adapt these types of interventions to support these families, recognizing that there may be differing needs within this community.

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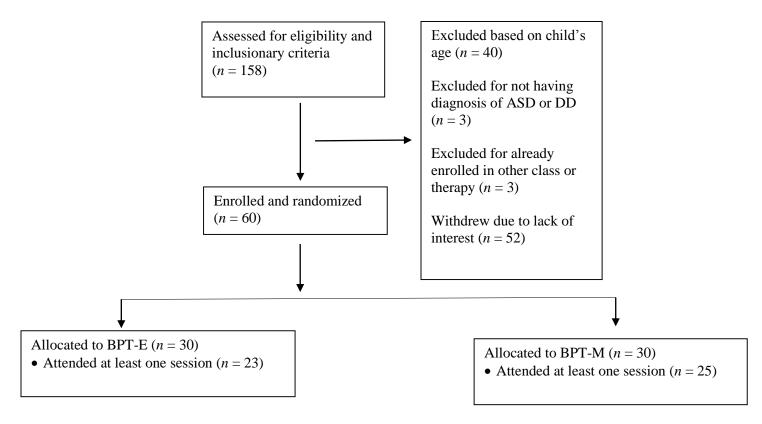


Figure 1. CONSORT diagram of participant inclusion within the Spanish cohort.

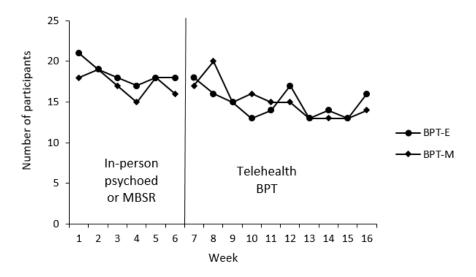


Figure 2. Spanish cohort caregiver attendance by intervention session.

Table 1. $\label{eq:Descriptive Statistics for Spanish-speaking Cohort Participants (N=60) }$

| Demographic | BPT-E (<i>n</i> = 30) | BPT-M $(n = 30)$ | | |
|--|------------------------|------------------|----------|------|
| | M (SD) or % | M (SD) or % | t | p |
| Target Child (TC) Age in Years | 3.90 (0.71) | 3.87 (0.90) | 0.16 | .874 |
| Primary Caregiver (PC) Age | 39.83 (7.12) | 38.83 (8.89) | 0.48 | .633 |
| PC Baseline Stress (PSI) | 113.23 (22.34) | 118.28 (18.87) | -0.94 | .354 |
| Child Total Problems Raw Score (CBCL) | 73.89 (31.55) | 86.66 (34.98) | -1.45 | .154 |
| PC Acculturation (VIA Mainstream Subscore) | 64.67 (21.22) | 61.62 (14.09) | 0.56 | .579 |
| | | | χ^2 | |
| Household Income (< \$30,000) | 53.33% | 63.33% | 0.62 | .432 |
| PC Education (No HS Diploma) | 50.00% | 66.67% | 1.71 | .190 |
| PC Sex (female) | 100.00% | 96.67% | 1.02 | .313 |
| TC Sex (male) | 63.33% | 76.67% | 1.28 | .260 |

Note. There were no significant between-group differences on any demographic variables.

Table 2.

Representative Participant Quotes Across Themes

| Theme | Representative quote (original) | Representative quote (translated) |
|-------------------|---|---|
| Inconsistent Use | Sinceramente yo no he practicado mucho la respiración. Al principio | Honestly, I have not used the breathing much. At first when I was |
| of MBSR | cuando lo practicaba, sí sentí que me ayudó bastante. Me sirvió lo | practicing it, I did feel that it helped me a lot. I was helped by what I |
| Strategies | que aprendí de no estarme preocupando por las cosas que van a | learned about not worrying about things that will happen. It has |
| | pasar. Sí me ha servido un poco para menos estrés, pero | helped me a little to [have] less stress, but honestly I have not |
| | sinceramente no lo he practicado. Se me olvida, no tengo el tiempo, | practiced it. I forget, I don't have the time, I always have many |
| | siempre tengo muchas cosas qué hacer y termina olvidándoseme. | things to do and I end up forgetting about it. |
| Satisfaction with | A mí me sirvió desde el principio, desde que empecé con ustedes | It helped me from the beginning, since I started with you with my |
| Psychoeducation | con mi hijo. Ha cambiado mucho, de hecho vamos a tener el IEP de | son. It has changed a lot. In fact, we are going to have my son's IEP |
| | mi hijo el jueves. También le pedí a la maestra, porque ella me | on Thursday. I asked the teacher, because she sent me a message |
| | mandó un mensaje diciendo, "El miércoles yo te mando los papeles | saying, "On Wednesday I will send you the IEP papers"; I said, "No, |
| | del IEP", le dije, "No, necesito que los mandes antes porque yo | I need you to send them before because I need to review them, see |
| | necesito revisarlos, ver que todo esté bien y también necesito decirte | that everything is okay and also I need to tell you that my son's |
| | que la coordinadora de mi hijo de regional center va a estar en la | coordinator from the regional center will be at the meeting, [his] |
| | junta, también ABA va a estar en la junta, la supervisora y la que | ABA [team] will also be at the meeting, the supervisor and the one |
| | viene a la terapia a mi casa también". No le pregunté, más bien le | who comes to my house for therapy as well." I didn't ask her, rather |
| | dije, "Espero que esté bien", porque yo sé que va a estar bien. | I said, "I hope that's okay" because I know it's going to be okay. |
| Satisfaction with | La parte que a mí más me gustó fue la primera, donde conocí a otros | The part that I liked the most was the beginning, where I met other |
| Sense of | papás, donde escuché las historias, donde me sentí entendida, saber | parents, where I listened to the stories, where I felt understood, |
| Community | que no estoy sola, que no soy la única mamá o papá en esta ciudad, | knowing that I am not alone, that I am not the only mother or father |
| | en este mundo. | in this city, in this world. |
| | | |
| | Oír experiencias de otros te sirve, lo que no me funcionó a mí a lo | Hearing experiences from others helps you, what didn't work for me, |
| | mejor a ellos les funcionó. Agarras experiencia, porque es muy | maybe it worked for others. You take in all these experiences, |
| | variado, el aprendizaje es sin límite. No hay un niño igual, lo que le | because it is very varied, learning is without limit. There is no child |
| | sirve a uno a otro no, pero a veces es bueno saber diferentes técnicas. | that's the same [as yours], what works for another doesn't always |
| | Especialmente si viene de la experiencia de otro papá. | work for you, but sometimes it is good to know different techniques. |
| | | Especially if it comes from another parent's experience. |
| Feasibility of | Pienso que los elogios Para mí ha funcionado muchísimo los | I think that praise praise has worked very well for me. They, I have |
| Behavioral | elogios. Ellos, yo tengo dos que son gemelos, se frustran mucho, y | two that are twins, they get very frustrated, and to help them do |
| Strategies | para ayudarlos a hacer alguna cosa, y que no se estén frustrando | something, and so that they are not so frustrated when they are doing |
| | tanto cuando están haciendo siempre les digo, "Estás haciendo muy | it, I always tell them, "You are doing very well," or "good job" I |
| | bien, o good job." A veces, hasta digo, "Sueno como mucho," pero | see that they get motivated, and that helps a lot. Also, another thing |
| | yo veo que se motivan, y les ayuda bastante eso. También otra de las | is the rewards. It is also something that works well for me for all |
| | cosas es las recompensas, también es algo que me funciona mucho | their behaviors. |
| | para todos sus comportamientos. | |

| Feasibility of Incorporating Other Family Members | Es de mucha ayuda, tanto para nosotros como padres y la familia, porque somos al menos de mi parte, soy de las personas que comparten con toda la familia, trato de compartir todo lo que aprendí, para que así el día de mañana si ven a mi hijo solotienen el pensamiento de educarlo. | It is very helpful, both for us as parents and the family, because we are at least on my end I am one of those people who shares with the whole family. I try to share everything I learned, so that tomorrow if they are with my son alonethey have the knowledge to take care of him. |
|--|--|--|
| | También trato de ignorar las cosas que no quiero que haga. A veces es un poco difícil porque mi esposo ahorita está aquí y él le hace caso, quiere llamarle la atención y no estamos en lo mismo, pensando igual. Porque a veces le digo, "Ni siquiera voltees a mirarlo, porque eso ya está llamando tu atención. No le digas nada". Es un poquito difícil porque yo lo quiero hacer de una forma y él hace otra cosa. | I also try to ignore the things I don't want him to do. Sometimes it's a bit difficult because my husband is here right now and he pays attention to him; he wants to get his attention and we are not on the same page, thinking the same. Because sometimes I tell him, "Don't even look at him, because that's already getting your attention. Don't say anything to him." It's a little difficult because I want to do it one way and he does something else. |
| Cultural Acceptability | Sería muy difícil me imagino, entender a todas las culturas que estábamos ahí. La verdad me gustó la manera que se tocó porque no fue nomás, "Okay, los mexicanos educan a sus hijos haciendo esto y esto", sino que fue universal para todos. De hecho me gustó eso porque no sentí discriminación hacia ningún tipo de raza que estábamos ahí, esa es mi opinión. | It would be very difficult, I imagine, to understand all the cultures that were there. I really liked the way it was handled because it was not just, "Okay, Mexicans educate their children doing this and this," but rather it was universal for everyone. In fact, I liked that because I did not feel discrimination towards any type of race that was there. That is my opinion. |
| | Acerca de los videos, a mi parecer, se me hacen como que estaban muy acartonados, para mi pensamiento se requería de unas personas más sinceras, porque como que no tomamos en cuenta si se podrían utilizar con personas que realmente son latinas, eran videos de personas que hablan inglés, había un intermediario para que nos lo dijera en nuestro idioma y para hacer esos grupos para personas latinas sería mejor utilizar padres que realmente son latinos y pudieran personalizarlo más en mi punto de vista. | About the videos, in my opinion, they seem to me to be very bland. For my thinking they required sincerer people, because it was as if they did not take into account if they could really be used with people who are Latino. They were videos of people who speak English, with an intermediary to tell us in our language. To do these groups for Latino people it would be better to use parents who are really Latino and could personalize it more, in my point of view. |
| Satisfaction with Delivery Modalities | Hacerlo por Zoom es la única opción ahorita pero cuando sea el mejor tiempo estaría mejor en persona, porque se aprende, conoces a la gente en persona, te vas familiarizando, vas dando tus puntos de vista, eso sí, prefiero yo mil veces en persona que por Zoom. Son como los niños, estamos pero de repente pasa alguien, ya nos distrajimos y lo que aprendimos se nos olvida. | Doing it through Zoom is the only option right now but when times are better it would be better in person, because you learn, you meet people in person, you become familiar, you give your points of view, yes, I prefer a thousand times in person than by Zoom. There are like the children, we are [in group] but suddenly someone passes by, we get distracted and we forget what we learned. |
| | Todo el desarrollo de lo que tuvieron ahora ustedes en este planteamiento que dieron con la plataforma Zoom, a mí se me hizo mucho mejor. La razón es que estaba en casa, más cómoda, estaba viendo a mis hijas, no tienes que trasladarte. Yo siento que hubo mucho mejor absorción de toda la información. | Everything you have developed now in this approach that you came up with on the Zoom platform, it became much better for me. The reason is that I was at home, more comfortable, I was seeing my daughters, you don't have to travel. I feel that there was much better absorption of all the information. |