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Parent Strategies Among Latino Parents of Children with Down Syndrome

Following a Parent-Mediated Social Communication Intervention

A thesis submitted in partial satisfaction

of the requirements for the degree

Master of Arts in Education

by

Maira Angela Tafolla Magana

2023

ABSTRACT OF THE THESIS

Parent Strategies Among Latino Parents of Children with Down Syndrome

Following a Parent-Mediated Social Communication Intervention

by

Maira Angela Tafolla Magana

Master of Arts in Education

University of California, Los Angeles, 2023

Professor Connie L. Kasari, Chair

Latino families of children with Down syndrome (DS) are underrepresented in social communication interventions. It is unclear whether interventions that primarily include non-Latino White, middle-class families also lead to positive social communication outcomes among children from culturally diverse backgrounds. The current study included a Latino sample (n=34) to assess to what extent parents of children with DS acquired the strategies of the parent-mediated social communication intervention, JASPER, and whether parent's level of education and primary language spoken at home (Spanish vs. English) influenced strategy uptake. The study also assessed language outcomes, measured using the Preschool Language Scale-5 (PLS-5; Zimmerman et al., 2011) and number of different word roots (NDWR) coded from a natural language sample, following intervention. Results suggest that parents of children with DS in the JASPER condition reached fidelity levels that were comparable to autism spectrum disorder

samples. The intervention improved children's NDWR significantly but did not have any effects on their PLS-5 scores.

The thesis of Maira Angela Tafolla Magana is approved.

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Table of Contents

List of Tables

Introduction

Latino families make up the largest ethnic minority in the United States and therefore comprise a large proportion of families with developmental disabilities including Down syndrome (DS). DS is a genetic disorder that affects cognitive abilities, social communication, and results in global developmental delays. Interestingly, children with DS display higher levels of social behaviors such as glancing at others' faces more often compared to children with and without other neurodevelopmental disabilities (Kasari & Freeman, 2001) but show delays in both verbal and nonverbal communication skills such as gesture use (Chapman, 1997; Dykens et al., 1994; Mundy et al., 1988; Mundy et al., 1995). While most individuals with DS remain language impaired throughout their lifetime, there is variability in language outcomes. It is unclear what contributes to this variability, but one factor that has been associated with language outcomes is environmental variation (Chapman, 2000), specifically the frequency of input children received from parents in daily interactions (Berger & Cunningham, 1983; Mahoney, 1988). The input that neurotypical children receive from their parents is theorized to differ based on cultural factors such as ethnicity and language and socioeconomic status (SES; Hoff, 2013; Romeo et al., 2018). Additionally, it is unclear whether parents' communicative behaviors influence child language outcomes or whether child characteristics and communication levels influence parent communicative behaviors, although most likely it is bidirectional. One study showed that parents respond proportionally to their children's communicative bids (Mahoney, 1988), meaning parents' responsiveness was contingent on children's level of verbal and non-verbal communication.

The hypothesized relationship between parents' communicative behaviors and child language outcomes has led researchers to target communication skills and language development

in children with DS through parent-mediated interventions in efforts to increase spoken language. There is some evidence that parent-mediated interventions for children with DS effectively increase communication skills such as the use of target words (a list of specific words selected by parents that were taught during the intervention), but results have been inconsistent across studies (O'Toole et al., 2018). Moreover, the existing literature is overwhelmingly non-Latino White and middle class with limited representation of Latino families from diverse SES backgrounds.

Differences in interaction styles between parent-child dyads have been associated with cultural factors such as race/ethnicity and language (Bornstein, 2012; Bridges et al., 2012; Hoff et al., 2019; Ochs & Schieffelin, 2011), and socioeconomic status (Rodriguez & Tamis-LeMonda, 2011; Romeo et al., 2018; Roopnarine et al, 2006) in addition to children's developmental disorder (e.g., ASD, DS, ID; Blacher et al., 2013; Crawley & Spiker, 1983). However, it is still less clear how linguistically and culturally diverse families from a range of socioeconomic backgrounds influence their children with developmental disorders' language outcomes through use of strategies (such as following the child's lead during parent-child interactions). The purpose of this study is therefore to explore whether parent sociodemographic factors including level of education and primary language spoken in the home (English or Spanish) are associated with strategy use during parent-child play interactions among Latino parents of children with DS before and after receiving the evidence-based parent-mediated intervention Joint Attention, Symbolic Play, Engagement and Regulation (JASPER; Kasari et al., 2021). Additionally, this study will assess whether JASPER leads to change in parent strategies among this culturally diverse group. Lastly, this study will explore the association between

JASPER strategies and child language outcomes before and after families participate in the intervention.

Literature Review

Culture, Sociodemographic Factors and Language

Cultural factors— race/ethnicity and language— shape the way parents interact with their children and therefore affect child language development (Bornstein, 2012; Bridges et al., 2012; Hoff et al., 2019; Ochs & Schieffelin, 2011). Regardless of cultural and linguistic differences between families, children's language trajectories seem to take a similar course of development in typical children; infants first babble, then they develop their first words, then phrases and so on. However, the way that language is taught can differ by culture and affect the rate in which language is acquired (Hoff, 2013). The theory of language socialization posits that parent-child interactions are influenced by cultural factors including the knowledge, ideas and the order of the social groups that the child is being socialized into, which in turn influences children's language use and language development (Schieffelin & Ochs, 1986). Sociodemographic factors such as SES also influence parent-child interactions and affect various forms of child outcomes including, but not limited to, social communication outcomes (Rodriguez & Tamis-LeMonda, 2011; Roopnarine et al, 2006). Additionally, it is unclear whether parents' primary language influences parent-child interactions, and parent strategies more specifically. One study found a significant association between primary language and strategies used during parent-child interactions among Latino families of typical children (Cabrera et al., 2006). Despite an extensive amount of literature describing the effects of parent-child interactions on language development in typical children, it is less clear what strategies parents from diverse cultural and

socioeconomic backgrounds use during parent-child interactions and how they affect language outcomes in children with neurodevelopmental disabilities like DS.

Communication Development in Down Syndrome

Individuals with DS show unique communication patterns, with strengths in receptive language and gesture use but significant delays in expressive language skills compared to typically developing children (Fidler et al., 2006). Expressive language delays become evident early on beginning with the delay of speech sounds and onset of first spoken words (Chapman, 1997). At a young age (i.e., 0-4 years old) children with DS will generally spend more time in the babbling stage than typically developing children (Stoel-Gammon, 1997), show delays in vocabulary development, nonverbal requesting, mean length of utterance, and language intelligibility relative to cognitive ability (Chapman & Hesketh, 2000).

Social Interactions and Development in Down Syndrome

Developmental theorist Vygotsky believed that children develop and learn through interactions with parents, siblings, other social partners, and their social contexts (Vygotsky, 1978). While social interactions occur naturally for parents and peers of typical children, social interactions with children who have developmental disabilities may not be as fluid given their communication delays. Individuals with limited language abilities may have a difficult time getting their point across or the social partner may have a hard time understanding, which can be frustrating for both people in the dyad and limit the quality of the interaction.

Despite communication difficulties, one of many strengths children with DS possess is their social nature and their social seeking behaviors. Children with DS show strengths in sociability and aspects of social-emotional development (Fidler & Nadel, 2007). During social interactions children with DS tend to orient toward other people significantly more than do

children without DS (Kasari et al., 1995; Ruskin et al., 1994) and will look at their social

partner's face more often than they look at nonfocal toys during play (Kasari et al., 1990). This

frequent social orientation gives more opportunities for children with DS to receive social input

from their partner (e.g., when a child looks up at his parent as he's playing with a car, the parent

might be more inclined to say "car" as opposed to a child who doesn't reference the parent).

While there seems to be more engagement between children with DS and their social partners,

there is less use of communicative symbols like gestures and words in their states of social

engagement (Adamson et al., 2012).

Joint Engagement and Language

Infusing symbols into joint engagement increases the quality of the social interaction

between dyads (Adamson et al., 2004). For an interaction to be symbol-infused joint

engagement it must be clear that the child is attending to both symbols and actions, objects or

events while referencing his play partner. For example, a child and his mother are building a

puzzle, the mother asks the child to "turn it around" and the child complies by turning the puzzle

piece around (Adamson et al., 2004). This is an example of a child attending to his mom's

language (symbol), which he demonstrates by responding to her directions. Compared to autistic

and typically developing children, children with DS spend less time in symbol infused joint

engagement. In other words, during interactions, children with DS spend some time interacting

with their partners but do not attend to symbols at the same rates as other children. Joint

engagement, and symbol infused joint engagement specifically, is strongly associated with

language outcomes (Adamson et al., 2009) which could partially explain the language delays

experienced by this group of individuals. Even though children with DS orient toward their

social partner's faces more often, social seeking behaviors are often used to avoid task-

persistence (Ruskin et al., 1994). The reluctance to attend to the environment and tasks at hand highlights a problem that children with DS face when coordinating joint attention (Landry & Chapiesky, 1987).

Avoiding task-persistent behaviors and problem-solving behaviors reinforces avoidant behavior and negatively affects task productivity. Kasari and Freeman (2001) reported that children with DS took significantly longer to complete a puzzle task and directed their attention toward the experimenter significantly more than children with and without other cognitive delays. Children with DS looked at the experimenter more, but they used their social behavior to distract the assessor from the task at hand rather than to ask for help, which affected task persistence negatively. A separate study investigated a puzzle completion task using possible shapes and impossible shapes that did not fit the puzzle with a sample of preschoolers with and without DS. There were no differences between groups in their abilities to complete the possible shapes, but their strategies differed when they worked on the impossible shapes; children with DS used "party tricks" to avoid and distract the therapist from the task at hand when cognitive demands increased (Pitcairn & Wishart, 1994). Task-avoidance behaviors and lack of persistence can affect naturally arising opportunities through which language is traditionally taught and have negative consequences for language learning among children with DS.

Parent-Child Interactions

Parent-child interactions— especially unstructured play interactions— among children with DS have been studied extensively, but effective strategies for improving language outcomes are less clear (O'Toole et al., 2018). Parent strategies are defined and coded in many ways; some studies focus on parenting responsiveness or sensitivity, some on directiveness and others create their own coding schemes that capture other parenting styles or strategies (Venuti et al., 2009).

One study analyzed parent-child interactions during unstructured (free-play) and structured (clean-up task and three problem-solving tasks) play assessments in children with developmental disabilities (i.e., DS, ASD, Cerebral Palsy and undifferentiated developmental delays) compared to neurotypical children (Blacher et al., 2013). The average age at entry was 35.3 months (SD= 3.1) and children were not matched on developmental level. Sixteen percent of all participants identified as Latino but the percentage of Latino families with DS specifically was not reported. The coding system employed by the researchers was composed of two factors, positive parenting and negative parenting. The "positive parenting" factor was made up of positive affect, sensitivity, stimulation of cognition, and detachment (reverse coded). The "negative parenting" factor included maternal negativity and intrusiveness. Child behavior problems were associated with parent strategy use during structured play interactions; parents used strategies like positive affect and responsiveness when children had less behavior problems which is consistent with other findings (Kasari & Sigman, 1997). Results from the study done by Blacher and colleagues (2013) also suggested that parents of children with developmental disorders used more "negative" parenting strategies compared to parents of typical children. During unstructured and structured play interactions parent education was a significant predictor of parenting strategy use; those with higher education levels had higher positive parenting and lower negative parenting scores for all groups. The study raises some issues about how parent behaviors are interpreted with codes clearly providing a positive and negative valence. The authors used the terms "intrusive" and "directive" interchangeably and attributed both to negative parenting behaviors whereas other studies recognize that directiveness can be an adaptive and positive strategy that parents use to teach children skills (Galeote et al., 2020).

Crawley and Spiker (1983) assessed mother-child interactions in children with DS through semi-structured play interactions, focusing specifically on parents' interaction styles. A prevailing belief at the time was that parents could not be directive and sensitive at the same time. Overall, being too directive was viewed as a negative parenting style. Yet for children who are severely delayed in their development, parents are often trying to teach them new things, and use directive strategies while teaching more often. In contrast with other studies, Crawley and Spiker (1983) found that parents could be both sensitive and directive simultaneously and that this combination of strategies yielded the best child outcomes.

Mahoney and Robenalt (1986) suggested that parents were more dominant and directive in conversations with their children with Down syndrome who communicated less. A later study by Mahoney further investigated the nuances of communication patterns between parent-child dyads with DS. Parents of children with DS were not necessarily more directive, but rather parents adapted their parenting styles to their children's characteristics and needs (Mahoney, 1988). All children included in the study were intellectually disabled and ranged in age from about 12 months to 37 months. Interactions of free play between the mother-child dyads were recorded and then transcribed for language and other communicative behaviors. A coding scheme was created to capture how each dyad responded to each other's communicative bids— responding communicatively, responding behaviorally, attending, or ignoring. Frequency of communicative behaviors between parents and children were calculated. Researchers found that parents matched the proportion of communicative bids to their children's communicative behaviors across all age groups; parents who have children that respond to communicative bids at higher rates will respond more to their children and parents who have children that ignore more will also ignore more of their children's communicative bids (Mahoney, 1988). The

nuances and differences in quality and quantity of communicative behaviors between parent-child dyads should be considered when thinking about parent-mediated interventions and identifying best practices that will lead to optimal language outcomes for children with DS.

Parent-Mediated Interventions

Parent-mediated interventions have aimed to improve child communication and language outcomes by teaching parents strategies that they can use with their children to target communication and language skills. Despite parents learning the strategies, positive communication outcomes for children with DS have been limited (Giralometto et al., 1998; Kaiser & Roberts, 2013; Karaaslan & Mahoney, 2013; Yoder & Warren, 2002). A randomized controlled trial (RCT) aimed to assess the efficacy of a social communication early intervention that included Responsivity training for parents and Prelinguistic Milieu Teaching for children (RPMT). The primary aim of the study was to assess the effect of RPMT on child communication outcomes (requesting and commenting) and parent strategy use, compared to parents and children in the control group. Their sample included 39 children with different neurodevelopmental diagnoses including DS (treatment= 8, control=9), and all participants had mental development indices below 70. No main effects of treatment were found on either child-initiated comments or requests (Yoder & Warren, 2002) but the intervention had positive effects on parental responsivity. Overall, research on parent-mediated interventions for children with DS to date warrant further rigorous investigations to better understand how parent gains could be transferred to affect child outcomes.

Furthermore, participation among Latinos in parent-mediated interventions for DS has been limited— families have not been included, or participant demographics have not been reported. This is surprising since there are indications that cultural factors affect parent attitudes

toward parent-mediated early interventions and strategy attainment in Latino families of typical children. For example, a Head Start study examined parent strategies by race/ethnicity and found that parents from different ethnic groups varied in directiveness during parent-child interactions such that African Americans were the most directive, followed by Mexican Americans; additionally, directiveness was influenced by parent education (Ispa et al., 2013). Furthermore, a qualitative study of parents whose children were enrolled in the CARING preschool program (Head Start) — a play-based parent intervention that aims to develop social-emotional development — found that Latino parents were not comfortable following their children's lead in interactions and were more used to directing the play (Duch et al., 2019). In contrast, a separate exploratory study found that Latino parents of children with ASD reported that strategies like following the children's lead were easier to implement while using strategies that frustrated the child were more difficult (DuBay et al., 2017). It is especially unclear whether certain types of parent strategies are more or less common among Latino parents of children with DS. As noted, there is empirical evidence that shows that parents of neurotypical children, and parents of children with different developmental disabilities use different strategies (Blacher et al., 2013). Therefore, extending intervention research into culturally diverse groups with children with DS remains an important question.

Even though parent-mediated interventions have not had striking effects on language outcomes to date among children with DS, these interventions remain promising avenues to ultimately affect child outcomes. Using an RCT, Kaiser and Roberts (2013) compared the effects of Enhanced Milieu Teaching (EMT) implemented by therapists vs. parent+therapist on child language outcomes in children with various neurodevelopmental disabilities (i.e., developmental delays, ASD, and DS). Both conditions were identical in dose; results suggested that after 12

months, children who were part of the parent+therapist group used more utterances than did the children in the therapist only group (Kaiser & Roberts, 2013). Most participants identified as White but ethnicity (e.g., Latino vs. non-Latino) was not reported in the study. We know very little about Latino parents' use of evidence-based strategies during interactions with their children with DS, although we expect cultural factors may affect the style of the interactions (Ispa et al., 2013; Duch et al., 2019). Thus, it is critical to assess Latino parents' use of language promoting strategies during interactions with their children with DS—strategies that have been developed and tested in non-Latino groups. Further, it is important to assess whether the use of these strategies influence children's language outcomes.

The Current Study

The current study aims to explore how a heterogeneous group of Latino parents of preschool aged children with DS take up strategies during a naturalistic developmental behavioral intervention trial. Parents randomized to the treatment group were trained to use the skills from the Joint Attention, Symbolic Play, Engagement and Regulation (JASPER) intervention, an evidence-based parent-mediated behavioral intervention (Kasari et al., 2021). This unique and diverse sample allowed for the rigorous evaluation of parent strategy use among Latino families during interactions with their children with Down syndrome before and after the intervention trial.

Research Aims

- Aim 1a is to assess whether there are differences in entry JASPER fidelity scores between mothers with lower education levels compared to mothers with higher education levels. Aim 1b is to assess whether mothers' levels of education influence JASPER fidelity at exit. Aim 1c is to assess whether there are differences in entry JASPER fidelity

scores between mothers with Spanish as their primary language compared to mothers who use English as their primary language at home. Aim 1d is to assess whether mothers' primary language at home influences JASPER fidelity at exit.

- Aim 2a is to assess whether treatment (JASP-EMT vs. waitlist) and exit JASPER fidelity scores are associated. Aim 2b is to assess whether mothers' levels of education moderate the relationship between treatment and JASPER fidelity scores at exit. Aim 2c is to assess whether mothers' primary language spoken at home moderates the relationship between treatment and JASPER fidelity at exit.

- Aim 3a is to assess whether JASPER fidelity at entry is associated with PLS expressive language scores at entry. Aim 3b is to assess whether treatment is associated with PLS scores at exit. Aim 3c is to assess whether JASPER fidelity at exit predicts PLS scores at exit. Aim 3d is to assess whether treatment moderates the relationship between JASPER fidelity at exit and PLS scores at exit.

- Aim 4a is to assess whether JASPER fidelity at entry is associated with number of different word roots (NDWR) at entry. Aim 4b is to assess whether treatment is associated with NDWR at exit. Aim 4c is to assess whether JASPER fidelity at exit predicts NDWR at exit. Aim 4d is to assess whether treatment moderates the relationship between JASPER fidelity at exit and NDWR at exit.

Hypotheses

We hypothesize that JASPER fidelity at entry will not differ between parents with different levels of education. While some of the strategies that make up JASPER may be more difficult for some parents, such as following the child's lead (Duch et al., 2019), overall fidelity scores will not differ. For similar reasons, we hypothesize that education levels will not moderate the relationship

between treatment and exit JASPER fidelity scores. Based on the limited literature, we did not generate a hypothesis for the effect of primary language spoken at home on JASPER fidelity at entry or exit and this aim remains exploratory. We hypothesize that there will be a positive and significant effect of treatment on JASPER fidelity from entry to exit. Finally, we hypothesized that higher JASPER fidelity scores at entry would be positively associated with children's language skills at entry and that there would be a positive relationship between JASPER fidelity at exit and language skills at exit, specifically for participants in the treatment group.

Method

Participants

The current study included 34 parent-child dyads self-identified as Latino. Children's average chronological age was 41.65 months (SD_{age}=7.40 months; 44% female, 56% male). The mean visual receptive (VR) age equivalent score was 23.58 months (SD=5.07 months). Of the caregivers who were enrolled in the study, 88% were mothers (M_{age} = 39.58 years, SD_{age}= 6.37 years). Fifty-six percent of the families used English as the primary language spoken at home, 41% used Spanish, and 1% used another language not specified. Tables 1 and 2 in the appendix include additional demographic information.

Participants were recruited through local organizations including early intervention programs, schools, and other community organizations across two large metropolitan areas as part of a larger multisite randomized controlled trial. Eighty-two percent of participants were from site one (University of California, Los Angeles) and 18% from site two (Vanderbilt University). Eligibility criteria included having a) a parent report of DS diagnosis, which occurs through blood tests that show a child has an additional fragment or full copy of chromosome 21 as discussed in the *Diagnostic and Statistics Manual of Mental Disorders* (5th ed.; DSM-5;

American Psychiatric Association, 2013), b) a mental age of at least 18 months as measured by the Mullen Scales of Early Learning (MSEL; Mullen, 1995) and c) an expressive vocabulary of less than 20 words in either or both languages (spoken or signed). Children with comorbid diagnoses were not eligible for participation (e.g., both autism spectrum disorder and DS). Institutional Review Boards at both sites gave approval for the study.

Procedure

Participants of the current study were part of a larger randomized controlled trial that tested a parent-mediated social communication skills intervention called JASPER-Enhanced Milieu Teaching (JASP-EMT). Participants were randomized into the JASP-EMT intervention (n=19) or waitlist control arm (n=15) by a researcher who was blind to treatment allocation. Children assigned to the waitlist control arm received intervention following the active period of the study. Parents were asked to fill out demographic forms that used multiple choice to gather information about race and ethnicity, family income, level of education, and the primary language spoken at home at Time 1 (pre-intervention). Participants completed observational and standardized assessments at three timepoints including Time 1 (pre-intervention), Time 2 (exit) and Time 3 (three months post-intervention).

Participants randomized to intervention received two one-on-one sessions (child-therapist) per week and two caregiver-coaching sessions per week where the caregiver, the child and the therapist were present (parent-mediated). The course of intervention was 12 weeks. Each session (parent-mediated and therapist-child) lasted one hour. Child-therapist sessions were conducted in the child's home and/or at the child's preschool, while caregiver-coaching sessions were delivered in the caregiver's home. Most child-therapist sessions were conducted in English and a few in Spanish, based on the child's needs. Caregivers were given the option of receiving

training sessions in either Spanish or English; bilingual therapists were trained to deliver the intervention in a culturally sensitive manner in both languages.

JASP-EMT

JASP-EMT is a blend of two evidence-based early interventions (JASPER and EMT) designed to teach play, target engagement, and support language development in children with DS. JASPER is a naturalistic, developmental, play-based behavioral intervention that targets children's engagement through play and promotes spontaneous initiations of social communication (Kasari et al., 2021). EMT is a naturalistic, conversation-based intervention that promotes and uses children's initiations and their interests to teach language (Kaiser 1993).

Measures

Parent Strategies Codes

A 10-minute caregiver-child interaction (CCX) during free-play was videorecorded for each dyad at each timepoint including entry, exit and follow-up. During the interactions parents were asked to play with their child as they normally would, using a kit of toys that were not used during the intervention sessions. Some examples of the toys available were puzzles, ring stackers, dolls, tea sets and furniture. The protocol for the CCX was translated to Spanish. Parents were rated on their use of engagement and regulation, environmental arrangement, balancing imitation and modeling, play routines, expanding play routines, joint attention and behavior regulation skills, and language strategies based on the Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) intervention protocols (Kasari et al., 2021) by independent coders who were blind to treatment allocation. Each strategy was rated using percentages that range from 0-100 which encompass the accuracy of parent use of each JASPER strategy (0% = no appropriate use of the strategy, 100% = use of strategy with the highest

accuracy possible). The seven JASPER strategies coded were averaged to create overall fidelity for each video. The coding procedure was the same for videos collected at entry and exit. A single blind coder was trained to code all the videos for the current study. Rating reliability was established between two independent coders using an independent set of videos until the primary coder reached a level of 80% percent reliability.

Preschool Language Scales-5

Children's expressive language abilities were assessed at the entry, exit and follow-up timepoints using the Preschool Language Scales-5 (PLS-5; Zimmerman et al., 2011). The PLS-5 Spanish version was used with children whose primary language was Spanish, as reported by parents. The PLS-5 yields raw scores, but they were converted to age equivalent scores. Age equivalent scores were chosen because they tend to be more sensitive to change over time compared to standardized scores (Grzadzinski et al., 2020).

The Natural Language Sample

A 20-minute adult-child standardized interaction was administered and videorecorded by a reliable researcher blind to treatment allocation. The assessment included a specific set of toys (e.g., bubbles, farm, cooking materials, and dolls) that the adult and child played and engaged around. The adult responded to all child communication but refrained from prompting spoken language. The videos were transcribed using the Systematic Analysis of Language Transcripts (SALT; Miller & Iglesias, 2012), and number of different word roots (NDWR) spoken were coded by research staff blind to treatment allocation. This type of measure has been used with children who have other types of developmental and communication delays and is effective in capturing spontaneous expressive language abilities (Tager-Flusberg et al., 2009).

Mullen Scales of Early Learning (MSEL)

The Mullen Scales of Early Learning (MSEL) was administered to participants at entry, exit and follow-up to assess child's cognitive abilities (Mullen, 1995). The MSEL captures 5 domains: (1) gross motor, (2) fine motor, (3) visual reception, (4) receptive language, and (5) expressive language. The domain of visual reception from the MSEL was used as a proxy for cognitive development. The raw scores were converted to age equivalent scores. The MSEL was translated to Spanish by the research team as needed (this assessment was not yet standardized in Spanish).

Statistical Analyses

Descriptive statistics and model diagnostic information were used to confirm that the assumptions (i.e., skewness, outliers, and normality of distributions) for the various models were met. To address aim 1a, a two-sample t-test was used to compare JASPER fidelity scores at entry between mothers with lower education levels (0 = attended some high school or below) and mothers with higher education levels (1= completed high school or above). For aim 1b, an ANCOVA was used with JASPER fidelity at exit as the dependent variable, mother's level of education as the independent variable, and baseline JASPER fidelity as a control variable. Mother's level of education was converted to a binary variable (0= attended some high school or below, 1= completed high school or above) due to the uneven distribution in responses across the categories. For aim 1c, a two-sample t-test was used to compare JASPER fidelity scores at entry between mothers who used Spanish as their primary language and mothers who used English as their primary language at home. For aim 1d, an ANCOVA was used with JASPER fidelity at exit as the dependent variable and primary language at home as the independent variable, controlling for baseline JASPER fidelity scores.

For aim 2a, an analysis of covariance (ANCOVA) was first used to assess the association between treatment and exit JASPER fidelity scores, controlling for baseline JASPER fidelity. Next, to address aim 2b and 2c, regression models were used to assess (a) whether mothers' levels of education moderated the relationship between treatment and JASPER fidelity scores at exit, and (b) whether primary language spoken at home moderated the relationship between treatment and JASPER fidelity scores at exit.

For aim 3a, Poisson and negative binomial models were used. Poisson and negative binomial models were tested using likelihood ratio tests to assess which model fit the data better. Binomial models are like Poisson models, with the difference that Poisson models assume that the mean and variance of the data are equal, while binomial models do not (King, 1989). The negative binomial model was used over the Poisson model if it was a better fit for the data. If the residual deviance for the model was significantly large compared to the degrees of freedom, it was an indication that the Poisson was not a good fit. Using a negative binomial model, we assessed whether JASPER fidelity at entry was associated with PLS expressive language scores at entry. For aims 3b, 3c and 3d, Poisson models were used to assess whether (a) treatment was associated with PLS scores at exit, using entry PLS scores as a covariate, (b) JASPER fidelity at exit predicts PLS scores at exit, using entry PLS scores as a covariate and (c) treatment moderates the relationship between JASPER fidelity and PLS scores at exit, using entry PLS scores as a covariate.

For aims 4a, 4b, 4c and 4d we used negative binomial regressions to assess whether (a) JASPER fidelity at entry was associated with NDWR at entry, (b) treatment was associated with NDWR at exit, using entry NDWR as a covariate, (c) JASPER fidelity at exit predicts NDWR at

exit, using entry NDWR as a covariate and (d) treatment moderates the relationship between JASPER fidelity at exit and NDWR at exit, using entry NSWR as a covariate.

<div align="center">Results</div>

JASPER Fidelity and Parent Sociodemographic Factors

Mothers with a high school education degree or above had JASPER fidelity ratings that were, on average, 10% higher at entry compared to parents who attended some high school or below (35.9% vs. 25.9%), R^2=.17, F(1, 31) = 6.193, β= 10.02, p=.018, 95% CI [1.81, 18.23]. However, there was no significant association between mother's level of education and JASPER fidelity at exit (47% for those who completed high school or above vs. 38.1% for those who attended some high school or less), controlling for JASPER fidelity at entry, R^2=.09, F(2, 29) = 1.383, β= 9.87, p=.122, 95% CI [-2.81, 22.56]. Primary language spoken at home (Spanish vs non-Spanish) was not associated with JASPER fidelity at entry (30% vs. 32.8%), R^2=.01, F(1, 31) = 0.399, β= 2.80, p=.532, 95% CI [-6.24, 11.84]. Additionally, primary language spoken at home was not associated with JASPER fidelity at exit (43.1% for Spanish as primary language vs. 43.8% for non-Spanish as primary language), controlling for JASPER fidelity at entry, R^2=.01, F(2, 29) = 0.107, β= -.06, p=.992, 95% CI [-12.46, 12.34].

JASPER Fidelity and Treatment Group

There was a significant effect of treatment on parent JASPER fidelity at exit, meaning that those who were randomized to the treatment group had significantly higher ratings of JASPER fidelity at exit than the control group, controlling for entry JASPER fidelity, R^2=.39, F(2, 29) = 9.271, β= 19.73, p<.001, 95% CI[10.27, 29.19]; average JASPER fidelity at exit for the intervention group was 52.3% and 32.9% for the control group, compared to 31.2% and 32.4% at entry, respectively. Furthermore, there was no evidence that mother's level of

education moderated the effect of treatment on total JASPER fidelity at exit, controlling for

JASPER fidelity at entry, R^2=.48, F(4, 27) = 6.329, β= 11.75, p=.206, 95% CI [-11.39, 16.45]. In

other words, mother's level of education did not influence the acquisition of JASPER fidelity in

either the intervention or control group. Additionally, there was no evidence that primary

language spoken at home moderated the effect of treatment on total JASPER fidelity at exit,

controlling for JASPER fidelity at entry, R^2=.42, F(4, 27) = 4.959, β= 10.83, p=.302, 95% CI [-

10.27, 31.93].

PLS Expressive Language Outcome

We found that JASPER fidelity at entry was positively and significantly associated with

PLS expressive language scores at entry (p=.04). We did not find evidence that treatment was

associated with PLS expressive language scores at exit, controlling for entry PLS expressive

language scores (p=.19). There was also no evidence that JASPER fidelity at exit was associated

with PLS expressive language scores at exit, controlling for entry PLS expressive language

scores (p=.70). Lastly, the relationship between JASPER fidelity at exit and PLS expressive

language scores at exit was not moderated by treatment (p=.21).

Number of Different Word Roots (NDWR) Outcome

Five outliers were identified in the NDWR variable coded from the language sample.

Two sets of models were run, one included the outliers and the other excluded them.

Additionally, there were three cases that had missing language sample data at either entry or exit;

for these models the total sample included 31 (outliers included) and 26 participants (no outliers

included).

Outliers Included

For the models in which the outliers were included, we found no association between JASPER fidelity at entry and NDWR at entry (p=.21). We found a positive and significant association between treatment and NDWR at exit, controlling for NDWR at entry (p=.006). At entry, the intervention group had lower NDWR on average (3.25), compared to the control group (9.2). However, even though the control group ended up with higher NDWR on average (12.5) compared to the intervention group (10.9), the intervention group made a larger improvement in NDWR from entry to exit (7.65 compared to 3.3). Additionally, we found a positive and significant association between JASPER fidelity at exit and number of different word roots at exit, controlling for entry number of different word roots (p=.03). We also found that the relationship between JASPER fidelity at exit and NDWR at exit was moderated by treatment (p=.04). Higher JASPER fidelity was associated with higher NDWR for those in the intervention group.

No Outliers Included

In the models that excluded the five outliers we found no evidence that there was an association between JASPER fidelity at entry and NDWR at entry (p=.55). We found a positive and significant association between treatment and NDWR at exit, controlling for entry NDWR (p=.04). At entry, the intervention group had lower NDWR on average (2.2), compared to the control group (5.5). The intervention group made a greater jump in NDWR from entry to exit (4.51 compared to a decrease of 0.17) and ended up with higher NDWR (6.71), compared to the control group (5.33). There was no evidence that JASPER fidelity at exit was associated with number of different word roots at exit, controlling for entry number of different word roots

(p=.09). Finally, there was no evidence that the relationship between JASPER fidelity at exit and NDWR at exit was moderated by treatment (p=.07).

Discussion

This study adds to the limited literature on parent-mediated interventions targeting social communication outcomes for children with Down syndrome. Additionally, a unique aspect of this secondary analysis is the focus on an entirely Latino sample. Socio-cultural factors can affect parent-child interactions, which can have important implications for children's developmental outcomes (Schieffelin & Ochs, 1986; Cabrera et al., 2006). However, most of what we know about parent-mediated interventions for children with DS comes from non-Latino White samples, and the use of cultural background/ethnicity as a moderator has not been widely explored (O'Toole, 2018).

The aims of the study were to assess Latino parents' response to the JASPER intervention by measuring their uptake of intervention strategies and determining whether sociodemographic factors such as level of education and language spoken at home would affect their response to treatment. Additionally, we were interested in assessing whether uptake of JASPER strategies would result in better language outcomes for preschool aged children with Down syndrome.

Caregiver Implementation of JASPER

The current study found a similar pattern in the use of JASPER strategies as a parent-mediated JASPER intervention study that was implemented in the community (Shire et al., 2022). Shire and colleagues (2022) found that parents had, on average, 35% fidelity scores at entry and 52% at exit, following 12 weeks of intervention (two sessions per week). Parents in the current study had comparable scores and entered the study with 32% JASPER fidelity scores and went up to 52% at exit, on average. Teachers and community providers that have participated in

JASPER randomized controlled trials have reached fidelity levels that range from 70% to 82% (Shire et al., 2019; Shire et al., 2022). It is seemingly more difficult for parents to take up the strategies, which could be due to many reasons, including but not limited to, levels of stress due to the burden of taking up an intervention. A psychoeducation study found that Latino parents of children with ASD reported higher levels of burden at the end of the study, after being taught evidence-based strategies by the researchers (Magana et al., 2017). A possible hypothesis presented by the researchers was that parents may become overwhelmed by the workload of the strategies. It is unclear whether parental burden was a factor that affected fidelity in the current study. Therefore, future studies should consider implementing an exit interview or a qualitative approach to data collection and analysis to understand what strategies parents find easy and which ones they find overwhelming and may need more support with. It is also of note that the intervention period for the current study was relatively short (12 weeks), which may inform the design and timeline of future parent-mediated interventions for children with DS.

Parents with higher levels of education had higher scores of JASPER fidelity at entry. However, regardless of education levels, all parents ended up with similar fidelity scores, on average, by the end of the study. Parental level of education is one of the strongest predictors of SES (Mistry et al., 2008); lower levels of socioeconomic status have been widely linked to negative child outcomes such as academic achievement, socio emotional abilities, and language abilities (Bradley & Corwyn, 2002; Sirin, 2005; Romeo et al., 2018). It is critical to highlight that these factors and child outcomes are greatly influenced by the systemic barriers that Latinos and many other groups face. These results highlight that regardless of level of education (and other potential barriers experienced), parents were able to make notable gains and uptake in JASPER strategies.

Additionally, there was no evidence that primary language spoken at home influenced fidelity levels before or after intervention. We did not have a hypothesis for this based on the limited literature. However, one study found that primary language was related to the strategies Latino parents used during interactions with their typical children (Cabrera et al., 2006). Results for the current study did not suggest any link between primary language spoken at home and JASPER fidelity, but subtler differences in language strategies could have gone undetected since JASPER fidelity is made up of a wide range of strategies including engagement and regulation, environmental arrangement, balancing imitation and modeling, play routines, expanding play routines, joint attention and behavior regulation skills, and language strategies. Future studies should continue to explore the relationship between primary language spoken at home and specific language strategies so that adaptations could be made to interventions if needed. Because language use in multilingual households can be so complex, detailed language analyses would provide researchers with important information regarding the link between primary language and specific language strategies, compared to a dichotomous variable like the one used in the current study.

Child Language Outcomes

Overall, treatment led to a larger increase in number of different word roots compared to the control group (for both samples with outliers and without outliers). Additionally, using the sample where outliers were excluded, parents in the treatment group who had higher fidelity scores at exit also had children with a higher NDWR. This suggests that that uptake of intervention strategies drove improvements in children's language outcomes, given the positive relationship between JASPER strategies and NDWR for those in the treatment group compared to the control group. Other parent-mediated trials looking at language outcomes in children with

DS have found their interventions to be mildly effective in changing expressive language outcomes (O'Toole et al., 2018). Kaiser and Roberts (2013) did not find any differences in language outcomes at exit but found that parent-mediated + therapist-mediated EMT increased child's utterances 6-months after the intervention, compared to the therapist-only group. It was hypothesized that positive results for children in the parent-mediated + therapist-mediated group were due to parents carrying out the strategies they learned over time.

One of the unique aspects of these data in the current study is that children's language was assessed across multiple contexts. When evaluating language outcomes using the PLS-5, which is a standardized norm-referenced measure, significant change over time was not observed; this could be due to the floor effects that were observed using this measure. Most children did not establish a true standard score because they scored low on the PLS-5. Future exploration of language assessments among this group is necessary to understand which measures capture true change.

Limitations and Future Directions

One of the main limitations of the current study was the small sample size. The statistical methods used are best fit for larger samples, though we were careful to assess that the data met all of the appropriate assumptions of the models that we used. We were not able to complete a sensitivity analysis however, to determine whether the results were consistent across the two sites. Additionally, this study did not report results from the follow-up visit due to the high levels of attrition at that timepoint and the already small sample size. Future studies should continue to track children over time to better understand whether early parent-mediated interventions have long term effects on language outcomes. Another limitation is that Latinos are a heterogeneous group from diverse countries, cultures, and backgrounds. It is important that future studies

collect additional demographic data such as country of origin and years living in the US, to determine whether groups differ in their use of strategies, as has been previously suggested in the literature (Tamis-LeMonda et al., 2012). Tamis-LeMonda and colleagues (2012) found that Mexican mothers differ in their gesture and language use compared to Dominican mothers, which may be directly related to children's levels of gesture and language use at 14 and 24 months of age. Further, language assessments should be tested further to determine which is the most effective in capturing change in language abilities in DS populations from diverse language backgrounds. Finally, future qualitative studies are necessary to understand parents' experiences participating in randomized-controlled trials. It is important to learn about parents' perspectives to understand what they found most and least effective and how they might be applying these strategies differently across their daily lives. As a result, researchers should take that feedback into consideration so that they address the needs of culturally diverse populations, and both adapt and create more culturally sensitive interventions. Adapted interventions that meet the cultural needs of families lead to higher engagement and intervention satisfaction (Parra Cardona et al., 2012), which can have important implications for achieving higher fidelity and retaining families in parent-mediated interventions, and better outcomes for children overall.

Conclusions

This study established preliminary evidence that the parent-mediated JASPER intervention is efficacious for children with Down syndrome. Children with DS increased their number of different word roots in a short period of 12 weeks. This study also showed that regardless of levels of education and primary language spoken at home, Latino parents made significant gains in the uptake of strategies of a social communication intervention that has primarily been tested with parents of children who have autism spectrum disorder. Parent-

mediated work should continue to include and focus on the needs of Latinos and other diverse groups with different sociodemographic backgrounds, so that interventions can be created, adapted, and tailored to meet their needs.

Table 1

Child Demographics

Measure	Variable	Value	DS (N=34) Mean (SD) or N(%)	Control (N=15) Mean (SD) or N(%)	Active (N=19) Mean (SD) or N(%)	p-value
Demographic	Child Age	Months (SD months)	41.64 (7.40)	41.00 (7.69)	42.20 (7.33)	0.37
	Gender	Male Female	19 (56%) 15 (44%)	7 (47%) 8 (53%)	12 (63%) 7 (41%)	0.54

Table 2

Parent Demographics

Measure	Variable	Value	DS (N=34) Mean (SD) or N(%)	Control (N=15) Mean (SD) or N(%)	Active (N=19) Mean (SD) or N(%)	p-value
Demographic	Mother's Age	(years)	39.58 (6.37)	39.71 (6.39)	39.47 (6.54)	0.69
	Father's Age	(years)	39.61 (7.84)	38.38 (7.29)	40.50 (8.31)	0.38
	Primary Caregiver	Mom Dad	30 (88%) 4 (12%)	13 (87%) 2 (13%)	17 (89%) 2 (11%)	0.99
	Primary Language Spoken at Home	English Spanish Other	19 (56%) 14 (41%) 1 (3%)	9 (60%) 5 (33%) 1 (7%)	10 (53%) 9 (47%) 0 (0%)	0.42
	Mother's education	Less than 7th Junior High	4 (12%) 6 (18%)	2 (13%) 2 (13%)	2 (11%) 4 (22%)	0.55

		Some High School	4 (12%)	2 (13%)	2 (11%)	
		High School	5 (15%)	3 (20%)	2 (11%)	
		Some College	4 (12%)	0 (0%)	4 (22%)	
		Special Training	1 (3%)	0 (0%)	1 (5%)	
		College	5 (15%)	3 (20%)	2 (11%)	
		Graduate School	5 (15%)	3 (20%)	2 (11%)	
	Income	<$10,000	3 (10%)	0 (0%)	3 (19%)	0.33
		$10,000-$19,999	5 (16%)	4 (29%)	1 (6%)	
		$20,000-$29,999	7 (23%)	3 (21%)	4 (25%)	
		$30,000-$39,999	5 (16%)	2 (14%)	3 (19%)	
		$40,000-$49,999	2 (7%)	1 (7%)	1 (6%)	
		$50,000-$59,999	0 (0%)	0 (0%)	0 (0%)	
		$60,000-$79,999	2 (7%)	1 (7%)	1 (6%)	
		$80,000-$100,000	2 (7%)	0 (0%)	2 (13%)	
		>$100,000	4 (13%)	3 (21%)	1 (6%)	

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