



A Randomized Waitlist-Control Group Study of a Culturally Tailored Parent Education Intervention for Latino Parents of Children with ASD

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Abstract

This two-site randomized waitlist-control study (n = 96 mother–child dyads) examined the efficacy of a psychoeducation program as compared to usual care to empower Latina mothers and improve their confidence in and use of evidence-based practices (EBPs) for their children with ASD. A secondary aim was to improve child outcomes. Compared to control group, we found significant positive changes in the treatment group in maternal confidence of and frequency in use of EBPs, child social communication and the number of EB services the child received. We found no significant differences for the treatment group in family empowerment or in child challenging behaviors. This RCT presents evidence of an efficacious intervention for Latino children with ASD and their mothers in California and Illinois.

Keywords Autism · Autism spectrum disorder · Latinos · Parent education · RCT

Introduction

Approximately 18.5 million children of Latin American descent (referred to as “Latino” in this paper) comprise 25% of all children aged 0 to 18 years in the US and represent the largest group of ethnically diverse children (US Census Bureau 2018). Estimates suggest that by 2050 Latino children will make up more than one-third of the US child population (Federal Interagency Forum on Child and Family Statistics 2012). Despite the large number and continued increase of Latino children in the general population, they are under-identified with autism spectrum disorder (ASD). Estimates indicate that the gap in ASD diagnosis

among White and Latino children has narrowed over time, yet Latino children remain under-diagnosed with ASD compared to their White and Black counterparts (Centers for Disease Control and Prevention 2018; Pedersen et al. 2012). While the national prevalence of autism is currently 1 in 59 children, or 1.7% of the child population, the current estimate for children with ASD in the Latino population is about 1% (Centers for Disease Control and Prevention 2018). Despite the fact that approximately 185,000 Latino children are diagnosed with ASD, very few service delivery and intervention approaches are tailored to meet the needs of Latino children with ASD and their families (Lopez 2014). Once diagnosed, persistent disparities for Latino children remain, including delay in age of diagnosis, access to services, utilization, and health care quality compared to their non-Latino counterparts (Casillas et al. 2017; Liptak et al. 2008; Magaña et al. 2013, 2016).

Disparities in ASD Diagnosis and Treatment Services Among Latino Children

In order to develop and tailor interventions for Latino children with ASD and their families, it is important to understand the sociocultural factors that contribute to barriers to care. Lopez (2014) adapted the socio-cultural framework for health service disparities (SCF; Alegría et al. 2011) to

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account for factors specific to the experience of Latino children with ASD and their families. Lopez (2014) emphasized disparities in age of ASD diagnosis and service access as a function of cumulative disadvantages across health care, educational, and community domains at micro, mezzo, and macro levels. She argues that by using a sociocultural framework lens, a more holistic perspective of the barriers and interactions across systems can inform interventions to reduce autism-related disparities among Latino children with ASD and their families.

At the micro level, child and parent factors may contribute to disparities. For example, greater severity of child symptoms and social impairments typically leads to greater service use and earlier intervention (Denney et al. 2007). However, among Latino children this may not always be the case (Magaña et al. 2016). Magaña et al. (2016) found that White children with ASD received more services if their functional severity was greater. In contrast, Latino children who had greater functional severity received the same number of services as Latino children with low levels of functional severity. Parent factors that may contribute to disparities include socioeconomic status, knowledge of ASD, nativity, health beliefs, and English proficiency (Magaña et al. 2013; Schieve et al. 2012; Zuckerman et al. 2017). Schieve et al. (2012), found that children whose parents were foreign-born were less likely to be diagnosed with ASD. Limited knowledge about ASD could be a factor for foreign-born parents, and in fact several studies have found that Latino parents reported limited knowledge about ASD and how to access information and services (Chlebowski et al. 2018; Iland et al. 2012; Magaña et al. 2013). In a study of Latino children with ASD, children of parents with limited English proficiency were found to use fewer ASD treatments and had greater unmet ASD therapy needs compared to English-proficient Latino parents, demonstrating that limited English proficiency can contribute to disparities (Zuckerman et al. 2017).

At the mezzo level, parent/provider interactions, provider bias, and lack of ASD-trained personnel may contribute to disparities for Latino children. For example, previous negative interactions with providers and lack of trust in service providers influence service use among Latino parents (Zuckerman et al. 2017). Furthermore, Latino parents reported confusion and inconvenience during the ASD diagnostic process indicating that some system-level changes are needed (Zuckerman et al. 2014). In a study of pediatricians and Latino families of children with ASD, Zuckerman et al. (2013) found that pediatricians reported challenges in assessing ASD risks among Latino children despite their familiarity and experience with Latino patients or appropriate screening tools. Further, Latino families reported limited access to developmental specialists (Zuckerman et al. 2013). The limited number of professionals trained to meet the cultural needs of the Latino population are insufficient

for the quantity of individuals needing services. The data suggests factors affecting the parent/provider relationship include stereotypes, prejudices, and statistical discrimination (Lopez 2014; Mandell et al. 2007).

Macro level factors influencing disparities include policy and social environmental attitudes on matters such as immigration that threaten access to services and impose fear of deportation among immigrant families (Ijalba 2016; Fountain and Bearman 2011; Welterlin and LaRue 2007). Health care policy can affect access to services and contribute to disparities. Many low-income Latino children rely on Medicaid for health insurance, which does not adequately cover diagnostic and evidence-based treatments for ASD in many states (Thomas et al. 2012). Whereas children who reside in families that have private insurance have more options to access these services.

Intervening to Address Disparities

Culturally tailored interventions are needed at all levels including healthcare and community systems to mitigate disparities among Latino children with ASD and their families (Lopez 2014; Pickard et al. 2016). There are a limited number of studies that have examined parent training interventions with Latino or low-resource families of children with ASD that have shown promise in improved parent and child outcomes (Buzhardt et al. 2016; Carr and Lord 2016; Kasari et al. 2014). While not fully culturally-adapted, these interventions made modest adaptations to engage low-resource families.

We developed a culturally tailored parent psychoeducational intervention that is focused on Latina mothers of children with ASD at the micro level; however, it is informed by research on the mezzo and macro levels within the intersection of the healthcare and community systems. The reader is referred to [citation and name of intervention omitted for blind review] for a detailed description of the intervention development and pilot study. In the pilot study, we used a one-group pre- and post-test design and found that parents significantly improved in knowledge about ASD, empowerment oriented family outcomes, and in confidence in using evidence-based strategies. Children with ASD significantly improved in parent reported language impairment. Outreach for participation in the program, intervention content, and delivery methods take into account the variety of barriers affecting Latino children with ASD and their families. We used a community-based method of intervention delivery, the *promotora* (community health worker) model, which has demonstrated efficacy in addressing health disparities in Latino communities (WestRasmus et al. 2012). Many health researchers and providers incorporate *promotoras* into health education interventions because they can add sustainability

while reaching Latino populations in a culturally sensitive way (Koskan et al. 2013). Promotoras are generally from the targeted community, speak the same language, and have connections to the community (Koskan et al. 2013). They receive training in the content area of the specific program and provide peer social support in addition to education (Magaña et al. 2014). While more common in providing education to Latino communities about chronic health conditions, the use of promotoras is emerging in educational programs about developmental disabilities and ASD (Magaña et al. 2014; Tapia et al. 2016). However, there are no randomized trials testing the use of promotoras for parent education in developmental disabilities and ASD.

Present Study

We conducted a randomized waitlist control two-site study to examine the efficacy of the intervention from December 2014 to December 2017. We compared the intervention condition to the control condition at two time points: baseline and follow-up (4 months after baseline). The focus of the intervention was on mothers and their confidence and use of knowledge and materials included in the intervention. However, we included child outcomes for potential distal effects. Our primary research question was: (1) Do participants in the intervention group show greater levels of empowerment, more confidence in using evidence-based (EB) strategies, and greater frequency in using EB strategies after receiving the intervention compared to participants in the control group? Based on our pilot study findings, we hypothesized that participants in the intervention group would improve in each of these outcomes compared to the control (citation omitted for blind review). The following two questions were exploratory: (2) Do children whose mothers received the intervention demonstrate fewer challenging behaviors, less impairment in social communication symptoms, and greater use of evidence-based services compared to children of mothers the control group? This is an exploratory question as we did not expect change in child behavioral outcomes because of recommendations that changes in children's outcomes require intensive behavioral intervention (Linstead et al. 2017). However, we hypothesized that children in the intervention group would increase their use of evidence-based services given the focus of the intervention to empower parents about accessing and advocating for services. (3) Do results vary by site, severity of autism symptoms, and child age? This is an exploratory question to determine whether the intervention works better for younger versus older children, for those with greater symptom severity versus less, and whether it works better for one site versus the other.

Methods

Intervention Description

The intervention is an in-home educational program targeted at the primary caregivers of children with ASD. The promotoras also had a child on the autism spectrum, were trained peer mentors and delivered the program in individual home-visits. Promotoras received 32 h of instruction in a group format to prepare them to lead program sessions. Program leaders presented and discussed session content and materials, and role-played activities with promotoras in the preparation training. Sixteen promotoras participated in the project, ten in Illinois and six in California. Each promotora had a caseload of one to three mothers at a time, and were compensated for the time spent on training and conducting individual home visits.

The 14-lesson intervention focuses on helping caregivers better understand their child with ASD, and identify any misinformation that they or other family members may believe about the condition. Caregivers learn about evidence-based methods to address the core features of autism. They also learn practical strategies that they can use at home with their children to improve daily functioning. The intervention aims to empower caregivers by teaching them advocacy skills to help them access evidence-based treatments and services. Sessions on reducing caregiver stress and expanding social support are important aspects of the program that aim to expand mothers' awareness of the need to take care of themselves, and their ability to do so.

The content includes the following topics: (1) introduction to the program; (2) understanding child development; (3) understanding the autism spectrum and your child's needs; (4) what works to address the symptoms of autism?; (5) how to be an effective advocate; (6) advocacy in the school system; (7) play together, learn together; (8) creating everyday opportunities to encourage communication; (9) helping your child make friends and interact with others; (10) challenging behavior is communication; (11) how to reduce challenging behaviors and respond appropriately when they occur; (12) reducing stress and recognizing signs of depression; (13) talking about autism to others and social support; (14) looking ahead.

Materials for the program included a promotora manual and a participant manual. The promotora manual included instructions to the promotora on how to deliver the content. The participant manual was given to the caregiver and included all of the content without the specific promotora instructions. Participants also received a folder with local community service resources. The folder could be referred to during the sessions, or used after the sessions to help

caregivers connect with and navigate the service system, based on their child's needs. Promotoras were equipped with a DVD containing video clips that relate to the lesson content and a portable DVD player. The DVD helped make the sessions more interactive, setting the stage for discussion between the promotora and the caregiver. Participants received their own copy of the DVD to use as a resource or future reference.

Home visit sessions were held weekly and each session opened with a check-into see how the participant's week went, and a review of the objectives for the lesson of the day. The session was delivered interactively, consisting of promoter presentation of the lesson content plus active discussions about the main ideas between the promotora and caregiver. The promotora would highlight important points and share personal examples from her experiences with her child and family. This personalization encouraged the caregiver to identify relevant examples and understand how the ideas relate to her and her child. The promotora also answered any questions that the caregiver had about the subject. In the process of sharing essential information, the promotora and the caregiver being mentored often built trust and relationships, leading to comfortable and productive exchanges. Each site had a promotora coordinator who supervised the promotoras and monitored fidelity. After each session, the promotora completed a fidelity checklist and contacted the coordinator by phone or email to report that the session was completed and to problem solve any issues. To enhance fidelity, study staff were assigned to observe two sessions for each promotora/participant dyad using the fidelity checklist. Both self-rated and observer-rated fidelity were above 90% and there were not differences between sites on promotora fidelity.

Participants

Parents of children with ASD ($n=96$) were recruited in two large urban areas in Illinois and California, through support groups of Latino parents of children with ASD, community organizations providing support to children with developmental disabilities, and schools. A larger sample was recruited from the Illinois site because additional funding was obtained for this site. The larger sample size allowed us to examine whether findings differ on child symptom severity, child age, and across the two sites. The groups and organizations shared brochures in both Spanish and English with eligible families. Inclusion criteria were: (1) mothers were of Latin American descent and resided in the target geographic areas, (2) the child was 8 years old or younger, and (3) the child had an ASD diagnosis or was determined to be at-risk for ASD and on a waiting list for evaluation of ASD. The content of the intervention was developed for parents who are just learning about autism because their

children were recently diagnosed or the parents never received adequate information since diagnosis. However, we extended the intervention for children up to age 8 years old because Latino children tend to be diagnosed later (Daniels and Mandel 2014; Valicenti-McDermott et al. 2012). Interested parents contacted study staff by phone or by sending in the reply tear-off from the brochure. Those who met study criteria were scheduled for a baseline assessment at which time they signed the informed consent and then completed the baseline assessment. While both parents were encouraged to participate in the intervention, mothers, who were the primary caregivers in all cases, were required to complete the assessments and intervention sessions.

Sample Size Calculation

Initial power analysis found that a sample of 22 in each group would provide at least 90% power to detect a minimum mean difference of 25% for the Family Outcome Scale and 80% power to detect a minimum group mean difference of 20% for the measure, Confidence in Use of Strategies. A larger sample was sought to examine our exploratory question of whether intervention results varied by site, child age, and level of severity of ASD symptoms.

Randomization and Allocation

As shown in Fig. 1, at the end of baseline data collection, mothers were assigned to the intervention now group or waitlist-control condition. Investigators at each site randomly assigned participants following confirmation of eligibility using a random number generator. Due to the nature of the intervention design, research coordinators and families were not blinded to group assignment; however, research personnel carrying out child assessments were blinded to group assignment. One hundred and twenty-seven mothers were screened and considered eligible for the study and 109 completed the baseline assessment. Of those screened that did not complete the baseline, we were unable to contact five to schedule baseline assessment, two withdrew for personal reasons, and 11 indicated they were not interested after the screening. Of the 54 intervention participants that completed baseline, 45 completed the 14-week intervention, which indicates an 83% retention rate. However, we were unable to reach three of them to complete the follow-up assessment. Nine intervention participants did not complete the intervention due to competing personal demands. Only one of the control group participants was lost to follow-up.

Demographic questions assessed at baseline included parent age, education level, household income, marital and employment statuses, perceived health status, and nativity; and child age, gender, and severity of ASD symptoms.

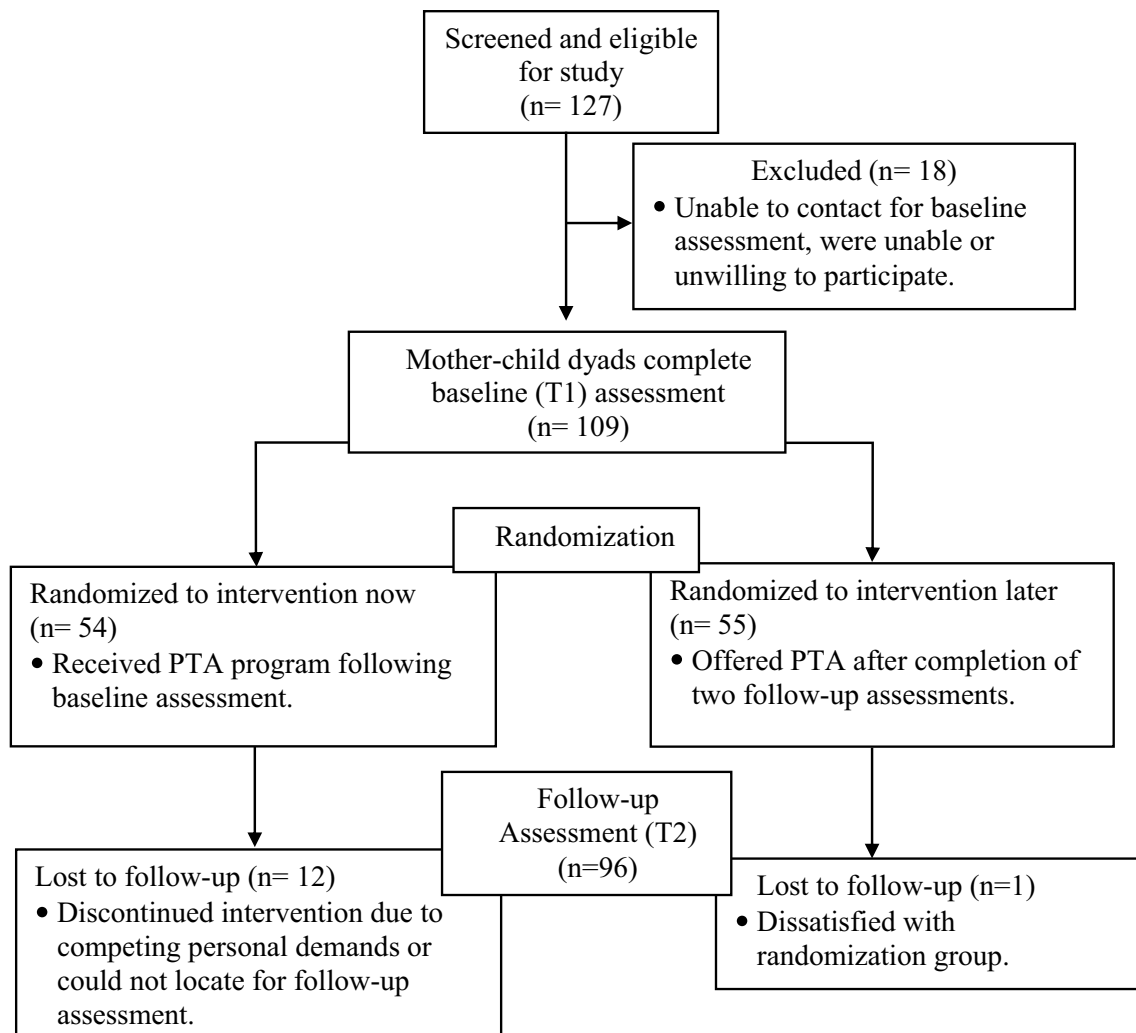


Fig. 1 Enrollment and retention flow chart

Table 1 shows demographics for 42 parents in the intervention group and 54 parents in the control group who completed the time 1 and time 2 surveys. Close to 90% of mothers were foreign born and 88% chose to receive the intervention is Spanish. The majority of mothers were of Mexican descent (78%), six mothers were from Central America (Guatemala, Costa Rica, Honduras, and El Salvador), four mothers were from the Caribbean (Puerto Rico, Dominican Republic, and Cuba), two mothers were from South America (Ecuador and Peru), and two mothers did not specify. The majority of mothers (80%) had household income levels under \$40,000 and a high school education or lower (71%). Mothers were on average 37 years old and about a third were employed. The majority were married or living with a partner (71%) and were in good or excellent health (59%). Four mothers had more than one child with ASD. The children were on average about 5 years old, and the majority were male (87%). Ninety-five percent (95%) of

the children in the study had a formal ASD diagnosis; five children were at risk for ASD. About 35% of children had severe symptoms of ASD.

With respect to differences in demographic characteristics between the intervention and control groups, annual household income, employment, marital status, foreign-born status, and self-reported health status were not significantly different, nor were any of the child characteristics. The only demographic characteristic that was significantly different was maternal education ($\chi^2 = 4.2, p < .05$). The control group had more mothers with less than a high school education and fewer mothers with a college degree than the intervention group (see Table 1). We also examined differences between California and Illinois families and found no significant differences. However, there was a marginal difference in maternal education between the two sites, 46% of the California mothers had a high school or more level of education, while the figure is only 22.9% for the Illinois mothers ($p = .075$).

Table 1 Demographics characteristics at baseline

Parents characteristics	Overall (N = 96)	Intervention (N = 42)	Control (N = 54)	Test value ^a
Age (standard deviation)	37.0 (6.2)	37.7 (5.7)	36.5 (6.5)	0.95
Level of education (%)				4.20*
Less than high school	35 (36.5%)	11 (26.2%)	24 (44%)	
High school	33 (34.4%)	15 (35.7%)	18 (33.3%)	
Some college or higher	28 (29.2%)	16 (38.1%)	12 (22.2%)	
Annual household income (%) ^b				0.08
Less than \$20k	30 (31.3%)	14 (35.9%)	16 (30.2%)	
\$ 20k–39.999	46 (47.9%)	16 (41%)	30 (56.6%)	
\$ 40k >	16 (16.7%)	9 (23.1%)	7 (13.2%)	
Employed (%)	29 (30.2%)	10 (23.8%)	19 (35.2%)	1.40
Married or living together (%)	68 (70.8%)	33 (78.6%)	35 (66%)	1.80
Foreign born (%)	86 (89.6%)	37 (88.1%)	49 (90.7%)	0.18
Good or excellent health (%)	57 (59.4%)	22 (55%)	35 (64.8%)	0.93
Site (%)				0.08
Illinois	70 (72.9%)	30 (71.4%)	40 (74.1%)	
California	26 (27.1%)	12 (28.6%)	14 (25.9%)	
Child characteristics	Overall (N = 100)	Intervention (N = 43)	Control (N = 57)	Test value ^a
Age (standard deviation)	5.31 (1.8)	5.44 (1.8)	5.21 (1.7)	0.64
Gender (%)				0.72
Male	87 (87%)	36 (87.7%)	51 (89.5%)	
Severity of ASD (%)				0.00
Severe symptoms	35 (35.0%)	16 (38.1%)	19 (33.9%)	

* $p < 0.05$ ^aT-test or Chi square values^bThe sample size for annual household income is 92 due to missing data

We also examined the differences in service utilization across the two sites and there was no significant difference found.

Measures

To answer our first research question, we measured family empowerment, confidence in use of evidence-based strategies, and frequency in use of evidence-based strategies at baseline and follow-up. All of these measures are based on parent report.

The Family Outcome Survey-Revised (FOS; Bailey et al. 2008) was used to assess family empowerment. It includes empowerment-oriented items expected to change through participation in early intervention programs for children with disabilities and their families. The FOS includes five subscales, understanding your child's strengths, needs, and abilities; knowing your rights and advocating for your child; helping your child develop and learn; having support systems; and accessing the community. It is comprised of 24

items, with 4–6 items per subscale. Responses range from (1) not at all to completely (5). Items were summed for each subscale, and a total FOS score was produced by summing all items. Higher scores indicate better outcomes. The FOS was previously translated and validated in Spanish (Olmsted et al. 2010). Chronbach's alphas for the current sample was 0.72 for understanding strengths; 0.82 knowing rights; 0.86 helping child develop and learn; 0.74 having support systems; 0.75 accessing the community; and 0.91 for the total overall score.

Confidence in using the intervention strategies was measured with 11 Likert scale items developed by the research team (originally titled efficacy in use of strategies) to assess caregiver confidence in their use of the evidence-based strategies included in the intervention curriculum. Sample items include, "I feel confident modeling for my child what I want him/her to do", "I feel confident in evaluating whether an intervention will be helpful to my child", and "I understand the purpose of antecedents/behavior/consequences (ABC) chart." The items were developed, translated, and

back-translated by the research team. Responses ranged from (1) strongly disagree to (4) strongly agree. Responses were added for a total confidence score and higher scores indicate greater confidence in using the strategies. For this sample the Cronbach's alpha was 0.81.

Frequency of using intervention strategies was measured with 14 items assessing how often caregivers used the evidence-based strategies included in the curriculum. The items were developed, translated, and back-translated by the research team. Responses ranged on a 4-point Likert scale from (1) never to (4) always. Sample items include "How often do you immediately reward your child for positive behaviors?", "How often do you use prompting to encourage your child to do what you are asking him/her to do?", and "How often do you provide your child with different choices to prevent challenging behavior?" Items were summed for a total frequency score, with higher scores indicating greater frequency of use. The Cronbach's alpha for this measure was .83.

To answer our second research question, we measured the child's challenging behaviors, impairments in social communication, and number of services received. All of these measures are based on parent report.

The Scales of Independent Behavior Revised (SIB-R; Bruininks et al. 1996) was used to measure the child's challenging behaviors. The SIB-R is comprised of three domains of behavior: internalizing (hurtful to self, unusual or repetitive habits, withdrawal or inattentive behavior), externalizing (hurtful to others, destructive to property, disruptive behavior), and asocial behavior (socially offensive behavior, uncooperative behavior). Parents are asked to indicate if their child engaged in each behavior in the last month by responding "yes" or "no." For behaviors marked "yes", respondents are asked to indicate the frequency and severity of the behavior. Frequency is rated on a Likert scale ranging (1) less than once a month to (5) once or more per hour. Severity is rated on a Likert scale from (1) not serious to (5) extremely serious. Frequency and severity ratings are matched with a "part score" specific to frequency, severity and the general maladaptive index or each of its subscales (internalized, asocial or externalized maladaptive indices). The age of the child also has a part score. The part scores are summed and then subtracted from 100. The maladaptive behaviors index value can range from +10 to -41 and below. The level of seriousness of the value ranges from "normal" (+10 to -10) to "very serious" (-41 and below). The SIB-R was already available in Spanish and used with Latino parents by previous researchers (Blacher and McIntyre 2006; Magaña et al. 2006). The Cronbach's alpha for this sample was 0.83.

The *Social Communication Questionnaire (SCQ; Rutter et al. 2003)* Current Form is a 40 yes-or-no item parent-report screener that evaluates communication skills and

social functioning in children who may have ASD. The SCQ Current Form focuses on the child's behavior over the most recent 3-month period. Items rated 'yes' are added for a total raw score. Lower scores indicate less impairment in communication skills and social functioning. The SCQ was previously translated and validated in Spanish (Vrancic et al. 2002). Chronbach's alpha for the current sample is 0.78.

The number and type of services used consisted of 20 service questions in the baseline and follow-up questionnaires. Mothers were asked whether their child was currently receiving a given service. We summed yes responses for two categories, evidence-based (EB) and typical developmental disability (DD) services, to determine the number of services children received at each time point. EB services consisted of naturalistic interventions, social skills training, applied behavior analysis, parent training, sensory integration therapy, video modeling, picture exchange communication, voice output communication aids, pivotal response training, alternative or augmentative communication services, and social narratives. Typical DD services included occupational therapy, speech therapy, physical therapy, nutrition/feeding consultations, respite care, psychiatric services, psychological services, recreational therapies, and case management or coordination.

To determine the severity of autism symptoms at baseline, we used the *Childhood Autism Rating Scale, 2nd edition (CARS-2; Schopler et al. 2010)*. The CARS-2 is an autism rating scale designed for use by experienced clinicians. The scale is comprised of 15 items across five domains to determine autism characteristics including social interaction, communication, restricted patterns of interest and stereotyped behavior, sensory issues and associated features, and thinking style and cognitive issues. Clinician ratings are based on direct behavioral observations. We summed all items to produce a total raw score.

Demographic questions assessed at baseline included parent age, education level, household income, marital and employment statuses, perceived health status, and nativity; and child age, gender, and severity of ASD symptoms.

Procedures

The Institutional Review Boards of the (removed for peer review), and (removed for peer review) approved this study. All participants provided written informed consent before completing baseline assessments. Mothers were scheduled for a follow-up assessment after the completion of the intervention or approximately 4 months after baseline. Two graduate students or a principal investigator conducted each assessment. At the baseline assessment, mothers were asked to bring their child with ASD in order to administer the CARS-2 to obtain severity ratings of ASD. One graduate student or principal investigator administered the CARS-2

while the other observed, then a student interviewed the mother while the other played with the child. At the end of the baseline assessment, mothers were informed of whether they would receive the intervention immediately or approximately 4 months later, after follow-up assessments were completed. Those receiving the intervention immediately were assigned to a promotora who followed up to arrange the first in-home visit and to arrange a compatible schedule to meet weekly. The children of mothers randomized to the waitlist-control group received usual care, which consisted of services such as speech and occupational therapies, and in some cases parents participated in support groups. They were offered the intervention after the follow-up assessments were completed.

Analysis

In order to answer the first two research questions, we conducted a bivariate analysis on participant and child characteristics by treatment group with *t* test and Chi square tests to identify and control for any treatment group differences in the main analyses. We then utilized mixed effects linear regression models for all outcomes and adjusted for level of maternal education (as this was the only demographic variable that was significantly different between the two groups) and study site. To discern whether there was a treatment effect between baseline and time 2 measures, we included an interaction term in all models, time \times treatment group, with time 2 and the control group as the reference categories. We included random slopes for each participant. The following parent outcomes were examined: confidence in using strategies, frequency of using strategies, the family outcomes scale and its subscales (understanding child needs and strengths, knowing your rights, helping your child develop and learn, having support systems, and accessing community). The child outcomes examined under the same model were SCQ score, number of current typical services, number of current evidence-based services, and the child maladaptive behaviors index.

To answer research question 3, we sought to ascertain differences in findings by the study site, autism severity, or child age (dichotomized by ages 2–6 vs. 7–8). We did this by conducting linear regressions on all time 2 (post-test) outcomes as the dependent variable and time 1 outcomes and an interaction term with intervention group and each of the independent variables identified above (including the single terms). Lastly, if differences in the treatment effect by the aforementioned independent variables were identified, we conducted separate repeated measures ANCOVA by site for all significant outcomes identified in the linear regression analysis by the categories of the independent variable and including an interaction term for treatment group and time. This was done to ascertain the differences in treatment effect

by site. For both analyses, we adjusted for maternal education as it was significantly different in the bivariate analysis. All analyses were conducted in SPSS 25.

Results

In our first research question, we asked whether there were changes in parent outcomes for the intervention group between baseline and follow-up. Table 2 shows the means and standard deviations of baseline and follow-up for the treatment and control groups, and the mixed effect model statistics. Mothers in the intervention group scored 4.5 points higher on average in the confidence in using strategies scale, indicating greater reported confidence using the EB strategies taught in the program at posttest. They scored 3.1 points higher on average in the frequency of using strategies scale compared to the control group, indicating that they reported using the EB strategies more at posttest; both results were significantly different. There were no significant differences in the family outcomes scale or subscales.

For research question two, there were significant differences in two child outcomes (see Table 2). Children of mothers in the intervention group saw a mean decrease in the *Social Communication Questionnaire* (SCQ) score by nearly two points on average compared to those in the control group, indicating reductions in impairment for children whose mothers participated in the intervention. There was also a significant increase in evidence-based services for the intervention group children. Children in the intervention group received almost one additional EB service between pre- and post-test. There were no significant differences in typical DD services and generalized maladaptive behaviors scale scores.

In research question three, we asked whether there were differences in the treatment effect for all parent and child outcomes based on child age, autism symptom severity and intervention site. An OLS regression was conducted on the interaction between treatment group and child age, symptom severity and site. We did not find differences in the dependent variables by child age or symptom severity. However, we identified significant differences in the treatment group by site (California vs. Illinois) for the overall family outcomes scale, knowing your rights subscale, accessing the community subscale and the SCQ score (see Table 3). On average, California parents saw an increase of 13.2 points in the family outcome scale, an increase of 4.1 points in knowing your rights subscale and an increase of 4.4 points in the accessing the community subscale compared to Illinois parents. California parents reported an average decrease of 6.1 points in SCQ scores for their children over Illinois parents (a mean decrease in SCQ score is the desired result as it shows less impairment).

Table 2 Means, standard deviations, and mixed effect model statistics for parent and child outcomes

Parent outcomes	Intervention		Control		Estimate/ standard error	t	p value
	T1	T2	T1	T2			
	(n = 42)		(n = 54)				
Confidence in using strategies	33.7 (5.9)	38.4 (4.5)	35.0 (5.5)	35.2 (5.3)	4.5 (1.2)	3.9	.000
Frequency of using strategies	40.5 (7.2)	45.6 (6.6)	41.1 (7.7)	43.2 (7.6)	3.1 (1.3)	2.4	.018
Family Outcome Scale (total score)	63.4 (17.9)	72.3 (14.1)	62.3 (15.6)	67.6 (16.8)	3.6 (2.7)	1.3	.192
Understanding child strengths and needs	11.6 (3.0)	13.5 (2.2)	11.5 (3.3)	12.6 (3.2)	0.9 (0.6)	1.4	.166
Knowing your child's rights	10.5 (5.2)	12.6 (4.1)	9.9 (4.8)	10.8 (5.7)	1.2 (0.9)	1.3	.206
Helping child develop and learn	11.6 (3.9)	13.2 (3.0)	11.6 (3.4)	12.3 (3.3)	0.9 (0.7)	1.4	.178
Having support systems	12.3 (4.9)	13.6 (4.6)	11.7 (5.1)	13.2 (5.3)	−0.3 (0.9)	−0.3	.763
Accessing the community	17.4 (4.8)	19.5 (3.9)	17.6 (4.5)	18.8 (4.1)	0.9 (0.8)	1.1	.269
Child outcomes	Intervention		Control		Estimate/ standard error	t	p value
	T1	T2	T1	T2			
	(n = 43)		(n = 57)				
Social communication	18.4 (6.0)	17.1 (5.8)	18.7 (5.4)	19.1 (5.7)	−1.8 (0.8)	−2.2	.033
Challenging behaviors	−10.5 (10.8)	−9.8 (9.9)	−12.2 (11.6)	−11.2 (11.0)	−0.3 (1.8)	−0.2	.866
Number of services							
Typical DD services	2.0 (1.2)	2.5 (1.5)	2.0 (1.3)	2.3 (1.3)	0.1 (0.3)	0.5	.615
Evidence-based services	.5 (0.9)	1.1 (1.4)	0.9 (1.4)	1.0 (1.4)	0.5 (0.2)	2.5	.014

Means and standard deviations are unadjusted. All mixed effects model analyses controlled for education, site and interaction. Estimates represent the interaction between time and intervention group

Table 3 OLS regression results for interaction terms site X treatment group, controlling for education level

Outcome	Estimate	SE	T-test	p value	95% CI	ANOVA F*
Family outcome scale	13.2	5.5	2.4	.018	2.3, 24.1	13.8
Knowing your rights	4.1	1.9	2.2	.031	0.4, 7.8	11.2
Accessing the community	4.4	1.5	3.0	.003	1.5, 7.3	11.3
SCQ	−6.1	1.6	−3.7	.000	−9.3, −2.9	29.2

*p values for all models were significant at <0.001

Reference groups: site, Illinois; treatment group, control; education level, some college or higher

Finally, we sought to better understand treatment effect differences by site found in the regression. Table 4 shows that controlling for education level, the California site saw a treatment effect for the total family outcomes scale, knowing your rights subscale, accessing the community subscale, and SCQ score. In contrast, the Illinois site did not show a treatment effect for these outcomes.

Discussion

In this study, we tested the efficacy of a psychoeducational program that aimed to empower Latino parents to advocate for evidence-based services for their child with ASD, and to feel confident using evidence-based strategies with their child to promote social communication and reduce

challenging behavior. We adopted a peer-mentor model in which Latino mothers in the ASD community served as peer educators or promotoras. To our knowledge, this is the first multisite study that used a randomized control trial to examine the use of a culturally tailored intervention for Latino parents of children with ASD.

The primary aim of the study was on improving parent outcomes and specifically promoting mothers' use of evidence-based (EB) strategies of with their children which were assessed in research question one. We found that there were significant positive changes from baseline to follow-up in the treatment group compared to the control group in both confidence in using evidence-based strategies and frequency of using these strategies. This indicates that parents felt more confident in using the EB strategies, and reported using them more at the time of the posttest.

Table 4 Differences in parent outcomes by site: repeated measures ANCOVA

Outcome ^a	Site	Intervention ^b		Control ^c		F test	p value
		T1	T2	T1	T2		
SCQ score	Illinois	18.2 (6.3)	18.4 (5.8)	18 (5.4)	18.4 (5.5)	0.0	0.947
	California	19.1 (5.1)	13.7 (4.6)	20.6 (5.1)	21.1 (6.2)	16.2	0.001
Knowing your rights	Illinois	11.2 (5.4)	12.0 (4.2)	9.6 (4.8)	10.7 (5.5)	0.1	0.703
	California	8.8 (4.3)	14.2 (3.7)	10.7 (5.0)	10.9 (6.3)	9.1	0.006
Accessing community	Illinois	18.3 (4.2)	19.4 (4.2)	17.9 (4.5)	19.5 (3.7)	0.5	0.489
	California	14.9 (5.5)	19.7 (3.2)	16.9 (4.8)	16.8 (4.7)	14.0	0.001
Total family outcomes	Illinois	66.4 (17.2)	71.8 (13.9)	61.9 (15.9)	68.5 (16.1)	0.1	0.740
	California	56 (18.0)	73.8 (14.9)	63.4 (15.2)	65.1 (19.0)	18.3	0.000

^aAll outcomes were controlled by education level

^bIllinois intervention group (n = 30); California intervention group (n = 12)

^cIllinois control group (n = 40); California control group (n = 14)

These findings are consistent with a study of parent education among low resource parents of preschoolers with ASD that found that parents reported high levels of using intervention strategies (Kasari et al. 2014). The other parent outcome we examined was the family outcome scale (Bailey et al. 2008), which was aimed at increasing parents' understanding of their children's strengths and needs, rights, how to help them develop and learn, and increasing the family support systems and access of the community. Contrary to our hypothesis, we found that there were no significant differences between baseline and follow-up on this outcome measure for the intervention group compared to the control group. To examine this issue further, we asked in research question three whether outcomes varied by site, child severity of ASD symptoms, and child age. We did not find variation on parent outcomes by ASD symptoms and child age, but we did find variation by site. The California intervention group showed improvement in knowing their child's rights, accessing the community and the overall family outcomes scale, while the control group did not. In contrast, the Illinois parents did not improve significantly in any of these outcomes. These findings may be due differences in sample sizes between the two groups; however, they may also reflect the fundamental differences in state policies and services between the two study sites as suggested by the socio-cultural framework described earlier (Lopez 2014). While parents from both sites were similar in services their children received (mostly occupational and speech language therapies), the DD service systems between the two states are quite different, which may offer an explanation. In California, there is the Regional Center system, which provides services as an entitlement for eligible children and their families (California Health and Human Services 2017). On the other hand, in Illinois, DD services are based on the state Medicaid waiver, which involves a long waiting list and a lottery system. We theorize that even in California where services are more robust,

Latino parents may start out with limited knowledge about autism, the service system, and how to access services (Chlebowski et al. 2018; Iland et al. 2012). Once parents are provided with the requisite knowledge and skills to access and navigate services, they can improve their child's access and increase family support, which may contribute to parental feelings of empowerment. However, in Illinois, even with greater knowledge and skills, parents may not be able to significantly increase family support and access to services for their children. These findings suggest that context matters, particularly with respect to state policy and service differences. Another potential explanation might be differences in promotoras and their supervision, although we did not find differences in promotora fidelity across the two sites.

The aim of research question two was determine if the intervention led to improved child outcomes. We did not hypothesize change in child outcomes because the intervention itself was limited to parents. Parent-mediated interventions (in which parents and child are present, and interventionists coach parents to use strategies with their child), have been shown to improve child outcomes (Linstead et al. 2017). Our intervention did not include coaching with the parent and child. We were interested in testing whether there were distal outcomes in which the parent education would lead to improvements for the children with ASD. Unexpectedly, we found significant improvement in child outcomes. Specifically, we found that the children whose parents were in the intervention group improved in social communication, showing less impairment, and in number of evidence-based services between baseline and follow-up, compared to the control group. These findings are consistent with a study that compared parent-mediated to parent education intervention among parents of children with ASD, which found that both types of interventions improved child outcomes, although the effect was stronger for parent-mediated intervention (Bearss et al. 2015). There were no significant

changes in challenging behavior and in the number of typical DD services (e.g., occupational, physical, and speech language therapies).

When we examined whether child outcomes varied by intervention site, we found that similar to some of the parent outcomes, the improvement in social communication was primarily driven by the California participants. As suggested earlier, it may be that once parents are empowered to tap into a robust DD services system, they can access additional supports that may lead to better outcomes for their children.

Limitations

While this study used a randomized waitlist-control design across two different sites, we note limitations to consider in interpreting the study results. First, the sample sizes in the two groups varied, and the sample size of the California site was relatively small. Small sample sizes may hinder the ability to detect effects and generalizability of findings to a larger study population. However, we note that the initial power analysis for the study indicated that 22 participants from each site would be sufficient and the California site exceeded this sample size. Second, the measures used in the study were all self-reported which may introduce social desirability bias into the results. Third, while we examined differences in demographic variables between the treatment and control groups, and adjusted for the variable that was significantly different, there may have been additional contextual variables that we did not measure. For example, systematic factors at mezzo and macro levels were not adjusted for, which may cause the differentiation of treatment effects across the study sites. Our study focused only on parents of children 8 years and under. A future study might examine the intervention with older children.

Conclusion

There are significant disparities in services for Latino children with ASD and their families (Casillas et al. 2017; Liptak et al. 2008; Magaña et al. 2013). With a predicted dramatic growth of this population within a few decades (Federal Interagency Forum on Child and Family Statistics 2012), there is a growing need to ensure evidence-based interventions are equitable. This study demonstrates efficacy of an intervention for Latino children with ASD and their parents in California and Illinois. Parents significantly improved in their confidence in and use of evidence-based strategies for their children with ASD, and the children with ASD improved in social communication and in receipt of evidence-based services. We found additional benefits to families in the California site, suggesting that policy and service context matters. Adding a parent/child coaching

component to the intervention may be especially important in regions where evidence based treatments are less available. This study contributes to the field of culturally-tailored interventions by demonstrating the importance of using culturally tailored approaches in autism intervention research, and showing that culturally-tailored interventions can be studied using a randomized control trial. It also expands the research on promotor models research demonstrating that this model can be used in autism education programs, in addition to educating communities about chronic health conditions.

To learn more about regional differences in intervention efficacy, future research should include more variables about the service systems and use multilevel or nested models to determine effects across multiple sites. Future research should examine intervention effectiveness across multiple sites, using implementation science goals to promote adoption of the intervention into routine systems of care. Future studies should use objective behavioral measures in addition to self-report. Because this intervention was developed to reach an underserved community, it may be beneficial to culturally adapt the intervention to other racial and ethnic groups that face disparities.

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Author Contributions SM & WM conceived of the study, developed the intervention content, participated in its design and coordination, and drafted the manuscript. KL participated in the design and coordination and contributed to the manuscript draft; KS participated in the coordination of the study and contributed to the manuscript draft; EL contributed to the intervention content, coordination of the study, and manuscript draft; MM & MGT conducted study analysis, and contributed to coordination of study and manuscript draft; WZ contributed to the manuscript draft and interpretation of results.

Compliance with Ethical Standards

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committees (name of universities withheld for peer review) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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