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Implementing an Intervention to Address Challenging Behaviors for Autism Spectrum Disorder in Publicly-Funded Mental Health Services: Therapist and Parent Perceptions of Delivery With Latinx Families

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Implementing an Intervention to Address Challenging Behaviors for Autism Spectrum Disorder
in Publicly-funded Mental Health Services: Therapist and Parent Perceptions of Delivery with
Latinx Families

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Abstract

Objectives: As implementation of evidence-based practices (EBPs) in publicly-funded children's mental health services has become increasingly common, concerns have been raised about the appropriateness of specific EBPs to the diverse client populations in these settings.

Exploring stakeholder perspectives can provide direction for refinements of EBPs when delivered with Latinx families. The current study used qualitative methods to examine therapist and Latinx parent perceptions of therapist-parent interactions and the intervention process when therapists are trained to deliver AIM HI (*An Individualized Mental Health Intervention for ASD*), a structured, parent-mediated intervention for ASD.

Methods: Therapist and parent participants were a subset of participants from a large-scale community effectiveness trial. Perceptions were gathered through focus groups with therapists (n=17) and semi-structured interviews with Latinx parents (n=29). Therapists were 94% female, 35% Latinx and 47% were fluent in Spanish.

Parents were 93% female, 100% Latinx and 66% preferred Spanish. A coding, consensus, co-occurrence and comparison approach was used to analyze data. **Results:** Three primary themes emerged: 1) limited parental knowledge about ASD and the need to address knowledge gaps; 2) differing perceptions regarding parental participation in treatment; 3) identification of influences on parent-therapist interaction, including the cultural value of *respeto*/deference (emphasized by therapists), and importance of *personalismo*/personal connection (emphasized by parents).

Conclusions: The themes provide specific direction for enhancements to AIM HI to maximize engagement of Latinx families. The themes also have broader implications for intervention development and community implementation including refinement of EBPs to facilitate fit and sustained implementation.

Keywords: Implementation, Training, Mental health services, Latinx, Latinx perspectives, Qualitative research, Autism Spectrum Disorder

Implementing an Intervention to Address Challenging Behaviors for ASD in Publicly-funded
Mental Health Services: Therapist and Parent Perceptions of Delivery with Latinx Families

Introduction

There are widespread concerns that community services for clients from ethnic minority backgrounds do not reflect evidence-based standards of care and there are documented disparities in Latinx children's experiences in mental health services (Alegría et al., 2008; Young, Klap, Sherbourne & Wells, 2001). Latinx children and adolescents are less likely to access mental health care referrals and services than their non-Hispanic White counterparts and often have unmet developmental or mental health needs (Alegría, Green, McLaughlin & Loder, 2015; Cook, Barry, & Busch 2013; Cummings & Druss, 2011; Garland et al., 2005; Kataoka, Zhang, & Wells, 2002; Wells, Hillemeier, Bai & Belue, 2009; Zimmerman, 2005). When receiving care, they are less likely to receive quality care (Alexandre, Younis, Martins, & Richard, 2010) and be satisfied with the care they receive (Coker, Rodriguez, & Flores, 2010; Flores, Olsen & Tomany-Korman, 2005).

Disparities are also documented for the specific population of Latinx children with Autism Spectrum Disorder (ASD) in access to diagnosis (Mandell et al., 2010), special education services (Harstad, Huntington, Bacic, & Barbersi, 2013), care from psychology/psychiatry providers (Broder-Fingert, Shui, Pulcini, Kurowski, & Perrin, 2013), and autism therapy services (Magaña, Lopez, Aguinaga, & Morton, 2013). Latinx children with autism and other developmental disabilities have more difficulty using services and obtaining appropriate referrals and have unmet routine or preventive care needs (Parish, Magaña, Rose, Timberlake, & Swaine, 2012). Overall, Latinx children with ASD are less likely to receive guideline concordant care

than non-Latinx white children with ASD on almost all quality of care indicators (Magaña, Parish, Rose, Timberlake & Swaine, 2012).

As the implementation of evidence-based practices (EBPs) in publicly-funded children's mental health services has become increasingly common (Brookman-Frazee et al., 2016; Bruns, Hoagwood, & Hamilton, 2008; Chorpita et al., 2011; Ganju, 2003; Schoenwald & Henggeler, 2004), concerns have been raised about the appropriateness of specific EBPs to the diverse client populations served in these settings. Implementation frameworks highlight the importance of fit of an EBP to the adoption, implementation, and sustainment of the EBPs (e.g., EPIS model; Aarons, Hurlburt & Horwitz, 2011) and the potential need for adaptations to ensure fit; however, Lau (2006) identifies the challenges of successfully adapting EBPs for specific ethnic communities given the paucity of empirical studies supporting that EBPs are effective or indicating that they are less effective for minority groups.

While disparities in access to health services for Latinx children and families are documented, less is known about how EBP delivery differs for ethnic minority families when therapists receive intensive and ongoing EBP training. The literature is very limited in this area with regard to the specific population of Latinx children with ASD. As a result, there is increased focus in utilizing an overall framework to guide investigative inquiry to understand and address disparities. The Socio-Cultural Framework for Health Service Disparities (SCF-HSD; Alegría, Pescosolido, Williams, & Canino, 2011) operates on the premise that health disparities emerge from interaction of disadvantages in health care and community systems. The SCF-HSD model proposes that social context impacts the access, quality, and outcomes of health care for racial and ethnic groups and that interaction between community and health treatment systems occur at every level – macro (societal, policy or environmental contexts), meso (community and

healthcare systems), and micro (individual factors and provider-client interactions). While other research inquiries have examined macro and meso level factors identified in this model (Derose & Baker 2000; Link & Phelan, 2005), investigation into micro factors can provide additional context for understanding disparities. In the current study, we use a micro level lens to focus on therapist-parent characteristics and interactions.

In psychosocial interventions for children, including those for ASD, parent involvement is considered a critical component of effective practice (Haine-Schlagel & Walsh, 2015). Parent engagement and participation in treatment sessions has been documented to be lower for Latinx families (as compared to non-Latinx White families) (Dickson, Zeedyk, Martinez, & Haine-Schlagel, 2017; Fawley-King, Haine-Schlagel, Trask, Zhang, & Garland, 2013). Lack of parent engagement has been cited as a barrier to delivering evidence-based interventions (Langley, Nadeem, Kataoka, Stein & Jaycox, 2010) and parental participation in treatment is related to improved intervention outcomes (Dowell & Ogles, 2010; Ingoldsby, 2010; Kamininski, Valle, Filene, & Boyle, 2008; Karver, Handelsman, Fields, & Bickman, 2006; Sanders & Kirby, 2012). This impact may be particularly relevant for children with autism as parent involvement is considered necessary to increase the intensity of intervention for the child (by extending skill-building outside of sessions) and for generalization of the child's skills developed during interventions (Brookman-Fraze, Stahmer, Baker-Ericzen & Tsai, 2006; Francis, 2005; Warren et al., 2011; Wong et al., 2015).

Understanding the impact of micro factors at both the parent and provider level can help provide direction for refinements to the delivery of EBPs for Latinx families. McCabe (2005) conducted focus groups and interviews with Mexican American parents and community therapists to obtain perspectives on implementation of parent-child interaction therapy (PCIT)

and gather recommendations to refine the intervention for the population. Findings indicating the presence of a relationship between parental attitudes and expectations and treatment withdrawal led to recommendations regarding the importance of considering treatment engagement when providing treatment to Mexican American parents. This included attending to parental engagement in an individualized manner when implementing the intervention (McCabe, Yeh, Garland, Lau & Chavez, 2005). A similar effort from Matos and colleagues (2006) utilized individual interviews with Puerto Rican parents and therapists with experience with a PCIT to identify appropriate cultural modifications for a culturally adapted model.

Consistent with the work that has been conducted to date, exploration of individual level factors benefits from the use of qualitative methods. The integration of qualitative approaches reflects a larger recognition of the need to broaden the perspective of clinical research to include a focus on the community based care context (Hohmann, 1999). Qualitative methods allow for deeper understanding by providing representation of perspectives of the participants themselves, as well as enhance the validity of collected data by allowing investigators to compare their interpretations to perceptions and lived experiences of the participants (Palinkas, 2014). In the current context, gathering in-depth information about therapist-parent interactions when therapists are trained to deliver a parent-focused intervention is highly important to understanding the fit of interventions within the psychotherapy context. Gathering perceptions on the nature of these interactions provides the opportunity to identify potential targets of training enhancement to facilitate implementation.

The aim of the current study was to use qualitative methods to examine therapist and Latinx parent perceptions of therapist-parent interactions and the intervention process when community therapists are trained to deliver AIM HI (*An Individualized Mental Health*

Intervention for ASD), a structured, parent-focused intervention for ASD designed specifically for delivery in publically-funded mental health services. A sequential qualitative research design utilizing focus groups and interviews was used to gather perceptions from therapists and parents. Results were used to identify provider training needs and specific direction for enhancements to AIM HI to maximize engagement of Latinx families as well as to more broadly inform community implementation of EBPs to facilitate fit and sustained implementation.

Method

Study Context

Data were collected in the context of a large-scale, randomized community effectiveness trial of *An Individualized Mental Health Intervention for Children with ASD* (AIM HI; Brookman-Frazee & Drahotka, 2010), a parent mediated mental health intervention designed to reduce challenging behaviors in children ages 5 to 13 years with ASD who receive services through the community and school based mental health programs. A randomized waitlist control design was used in the community effectiveness trial in which publicly-funded clinic and school-based mental health programs enrolled in the study were randomized to immediate AIM HI training/implementation or to a waitlist control/routine care observation condition. Therapist and client dyads were recruited from within enrolled programs. Therapists from programs in the training condition participated in a six-month training and implementation program. Specifically, they first received training in the AIM HI intervention via an introductory workshop and received a manual, protocol forms to use with clients, and access to resource website with fillable forms and video exemplars. Therapists then delivered the intervention to a participant child/family with consultation and performance feedback from an AIM HI trainer for six months. The community effectiveness trial provides a unique opportunity to examine differences in the psychotherapy process when community therapists are trained to deliver a structured protocol

that uses a parent mediated model. Change in therapist practice is the primary target of AIM HI training. The community effectiveness trial and the current study were conducted in compliance with the [MASKED FOR REVIEW] Institutional Review Board.

Participants

Participants in the current study include a subset of therapists who received training in the AIM HI intervention and Latinx parents of children with ASD who received the AIM HI intervention from participating therapists.

Therapist participants. Therapists were eligible to participate in the current study if they participated in the training condition of the AIM HI effectiveness trial and either identified as Latinx or were enrolled in the AIM HI study with a client or parent who identified as Latinx. Eligible therapists with (n=90) were contacted by mailing with information about the additional research activity and offered an invitation to participate. Three attempts were made to contact each eligible therapist. Of those contacted, 17 therapists responded to the invitation, participated in the focus group, and are included in the current analyses. Therapists in the current study did not differ significantly from non-participant therapists on age, gender, race/ethnicity, mental health discipline, years of clinical experience, or licensure status (*p*-values >.05 in one-way analyses of variance and chi-square analyses). Therapists were 94% female and an average age of 33.5 years old (*SD*=9.2; Range=23– 60). In the therapist sample, 35% self-identified as Latinx and 47% were fluent in Spanish. Therapist characteristics including education level, primary mental health discipline, years of clinical experience, trainee status (staff or trainee), and licensure status are reported in Table 1. Overall therapists in the current study were largely representative of providers working in community mental health setting in the geographic region (Bates, Blash, & Chapman, 2014; California Health Care Foundation, 2013).

[insert Table 1 here]

Parent participants. Parents were eligible to participate in the semi-structured interviews if they and their child participated in the AIM HI effectiveness trial (i.e. received psychotherapy services from a therapist receiving AIM HI training) and self-identified (through demographic information collected in the effectiveness trial) as Latinx. A total of 63 parents were contacted by mailing about the opportunity to participate in the research activity and of those, 38 contacted the research team and expressed interest in the study. Of the 38, 5 were unable to be contacted by phone for the interview and 4 were a “no show” for the scheduled interview and did not respond to follow up phone calls. Twenty-nine parents consented to participation and completed the interview.

Parents who participated in the interviews were 93% female, with an average age of 40 years ($SD=7.4$; Range=24-51). All 29 parents self-identified as Latinx; 86% were fluent in Spanish and 66% reported that Spanish was their preferred language (interviews were conducted in Spanish for these participants). Maternal level of education was primarily less than high school (42%) or high school/GED (31%). In regard to occupational status, 62% of mothers in the sample were homemakers, 28% worked full or part time, and 10% were unemployed. Household income for families fell below the federal poverty level for 52% of the sample. The children of the parents who participated in the interviews ($n=29$) were an average age of 9.8 years ($SD=2.06$). They were primarily male (90%) with cognitive functioning in the average range (average standard score of 90.4 ($SD=13.2$) on the Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II; Wechsler, 2011). The majority of the children (97%) identified English as their preferred language.

Data Collection

Data were obtained from therapist focus groups and individual semi-structured interviews with Latinx parents collected after 6 months of receiving service from a therapist trained to deliver the AIM HI intervention. Focus groups were utilized to allow participant interaction, promoting the sharing and collection of a diverse range of responses (Morgan, 1996), while individual interviews were used to explore identified themes in greater depth (Fontana & Frey, 2000). Data was collected in a sequential process with emergent themes identified from therapist focus groups utilized to inform the content of the parent interviews to allow for **data triangulation for** expansion and exploration of complementary themes. Integration of these methods was used to capture perspectives and themes that may have otherwise been overlooked (Morse, 2009).

Focus groups. A total of 6 focus groups with therapists were completed, moderated by the first or senior author. **Focus groups ranged in size from 2 to 5 participants based on participant scheduling availability. The first and senior author facilitated the focus groups. They are non-Latinx White females who were AIM HI experts, licensed clinical psychologists, with qualitative interviewing and coding experience. The 3rd author attended the focus groups to conduct the rapid assessment process. She is a Latina with Spanish as her native language. She had a bachelor's degree, was involved in coding video recorded therapy sessions for AIM HI fidelity, and had been previously training in qualitative data collection and coding.** Each focus group was 1.5 hours in length. The focus groups were **conducted in English**, audio recorded and transcribed. Focus group participants were compensated with a \$35 gift card.

Parent interviews. Interviews with self-identified Latinx parents were completed by phone by bilingual, bicultural research staff members. **Interviewers (n=2) were female, self-identified as multi-racial and Latina; both were native Spanish speakers. Interviewers had bachelor's degrees and experience conducting research interviews with parent participants and**

collecting qualitative data via interviews with participants. All interviewers were trained in qualitative data collection by the first or senior author. Interviews were conducted in parent's preferred language (English or Spanish); a total of 18 of the 29 interviews (62%) were conducted in Spanish. All interviews were audio recorded and transcribed in the language in which they were conducted. A professional transcription service (TranscribeMe) was used to transcribe the audio recordings. Recordings of interviews conducted in Spanish were translated by transcribers fluent in Spanish. Interviews were an average 44 minutes in length (range 28-76 minutes). Parents who completed the interview were compensated with a \$35 gift card.

Measures

Focus group guide. The therapist focus group guide was developed by study investigators in collaboration with a study consultant who specializes in the study of racial and ethnic disparities among children with autism and developmental disabilities. In the therapist focus groups, a semi-structured guide of open ended questions along with prompts and follow up responses was utilized. A funnel interview approach was used such that open-ended questions were asked first with specific follow up prompts. The open-ended questions asked therapists to share their perspectives and experiences with the AIM HI intervention process more generally. The follow up prompts were designed to understand whether therapists made specific modifications for Latinx families and elicit recommendations to determine whether revisions to the AIM HI training and clinical interventions protocol were indicated when delivering AIM HI with Latinx families. See Table 2 for focus group content areas and sample prompts.

[insert Table 2 here]

Parent interview guide. The parent interview guide followed a semi-structured interview approach with a pre-determined set of open questions and opportunities for the

interviewers to explore particular responses in more depth. The questions were designed to complement the preliminary themes identified in the therapist focus groups. Parents were asked questions pertaining to their autism literacy and their experience with mental health services. They were asked to share about their experiences participating in their child's treatment sessions with their AIM HI therapist and discuss factors that influenced their participation in sessions. Parents were asked about personal and family characteristics (including primary preferred language) and how these characteristics may have impacted their child's treatment. Parents were also asked to share perspectives on the AIM HI intervention materials and provide feedback about ways they could be improved. See Table 3 for sample questions from each of these domains.

[insert Table 3 here]

Data Analytic Plan

The data analytic plan for the current study was developed from the grounded theory method, an inductive process in which themes were generated from review of the data through an iterative process of data collection and analysis (Glaser & Strauss, 1967). Data utilized in the study include transcriptions and field notes documented during focus groups. Steps were taken to ensure the credibility, confirmability, transferability, and trustworthiness of the data, as defined by Wu and colleagues (2016).

Participants were recruited from both clinic and school-based care to capture perspectives across settings. The therapist focus groups were initially analyzed using a rapid assessment process (RAP), which is defined by Beebe (2001) as a qualitative inquiry approach that collects data through talking directly to participants and "getting them to share their stories" and utilizes triangulation and iterative data analysis and collection to quickly develop a preliminary

understanding of the collected qualitative data. A RAP was utilized to identify themes from the focus groups, which informed the parent interview data collection, allowing for data source triangulation (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). The focus group findings were initially categorized using notes taken in real time summarized into a template with domains pulled from the focus group guide. Transcripts of the focus groups were then reviewed to confirm identification of themes and identify additional relevant areas not initially included in the focus group guide. Peer debriefing between the first and senior author allowed for detailed discussions of the data and interpretation of the emerging themes. Initial results from the focus groups were reviewed by study investigators in order to inform the development of the parent interview guides.

The parent interviews were analyzed via a consensus coding process. A stepwise development of the coding system was employed starting with utilization of a codebook developed by investigators based on a priori themes informed by the existing literature, the therapist focus group, as well as the parent interview guide. The codebook contained definitions of codes, guidelines for use, and examples of representative quotes appropriate for inclusion in the category. All 29 transcripts were independently coded by four research assistants with training in qualitative methods; Spanish interviews were coded in Spanish by two bilingual, bicultural coders who are native Spanish speakers and identify as multi-racial and Latina. All coded transcripts were reviewed by a Ph.D. level clinical psychologist with experience with qualitative coding to allow for comparison of the codes and resolution of coding disagreements. Refinements to the codebook were made to capture emergent themes as initial coding occurred. Peer debriefing with the senior author was used to guide interpretations of the coded data and guide revisions to the codebook. The NVivo (QSR International, 2012) qualitative analysis

software program was used to analyze data through coding, development of categorical “nodes” consisting of related units of text, and aggregation of codes through the process of review and comparison in order to identify emergent themes and to ensure systematic analysis of coded data (Seale & Silverman, 1997).

In conducting the study, data were triangulated across sources (gathering information from therapists and parents), methods (utilizing both focus groups and semi-structured interview approaches) and investigators (multiple interviewers, transcripts coded by multiple coders, data analysis driven by interpretations from first and senior authors) (Creswell & Miller, 2000; Duffy, 1987). An iterative approach of revisiting data as questions and connections emerged and collecting additional data to confirm theories guided the process of data collection and analysis (Berkowitz, 1997). Data objectivity was maintained through investigator consultation with an expert not directly involved in data collection and analysis.

Results

Results indicate three primary themes related to the process of delivery of AIM HI with Latinx families including 1) *Limited ASD Knowledge* – limited parental knowledge about ASD diagnosis and symptoms and the need for extended pacing in treatment to address knowledge gaps, 2) *Expectations of parental involvement* – differing expectations between therapists and parents regarding parental participation in child’s treatment; and 3) *Influences on parent-therapist interactions* –recognizing the importance of the parent-therapist relationship and identifying influences on the relationship including the cultural value of *respeto*/deference (emphasized by therapists), and importance of developing *personalismo*/personal connection (emphasized by parents).

Limited ASD Knowledge and Need for Psychoeducation

There was a clear theme that emerged from both the focus groups and interviews around ASD knowledge with two subthemes: 1) Latinx parents' limited of knowledge about ASD and 2) the need for therapists to provide targeted psychoeducation to parents to address this knowledge gap. **This theme was identified by 72% of parents during interviews and discussed by providers in all of the focus groups.** When asked about her level of knowledge about ASD at the beginning of treatment one parent said, "Well, [I knew] nothing per se. I knew there was autism, that there was types of autism but not much per se. It was something new for me." This theme was commonly repeated during parent interviews, with one parent elaborating on the negative impact of this lack of knowledge:

There's a lot of parents don't have information when they [their child] first get diagnosed with the autism. They don't know how the child is going to develop or what's going to go on. Like when my first child, when he was diagnosed, it was devastating. Because you didn't know whether he was ever going to grow to be able to function by himself.

Therapists' responses echoed these themes with a therapist saying, "I brought it [child's ASD diagnosis] up with the mom once, and it was like she didn't understand what that was." Therapists repeatedly identified that Latinx parents were not familiar with ASD or the terminology surrounding the diagnosis. One therapist stated, "Families never experienced anything like autism or don't even have that word. It's not part of their vocabulary."

Recommendations for increased psychoeducation for parents around ASD came from both parents and providers. Parents identified the challenges of participating in treatment without initial ASD knowledge and the need for therapists to provide information early in treatment with one parent explaining:

What happens is that, it's because of a lack of information from the parents not knowing, and when the therapist starts saying things, the people get confused because they don't know. So then it's about going back to the beginning, it's to make the parents understand, give them an explanation... "What are autism's key points?" and that they can understand it, the children's actions, reactions, and behaviors.

During focus groups, therapists endorsed this as a relevant need for many of their families with one therapist stating, "I feel like more like 90% of our families would benefit from at least even just one session of psychoeducation about, what is autism and what does that look like."

During the interviews with parents, the topic of psychoeducation was explored in greater depth and parents were asked "Thinking back to your child's treatment, what type of information would you have liked to get from your child's therapist?" Parents were provided with several response options and the majority of parents reported that they were interested in "general information about autism and what a diagnosis of autism means," and endorsed wanting this introductory autism information more so than information about treatments or resources available for their child.

Therapists' discussion of parents' lack of ASD knowledge during the focus groups also highlighted a potential additional negative impact in that, in an attempt to fill in the gaps in their understanding of ASD, Latinx parents may resort to increased self-blame regarding the cause of their child's ASD. One therapist stated, "Latina mothers kind of do a little bit more of the self-blame in the sense that, culturally, you're the one that beared the child, so you must have given them struggles." Another therapist explained:

I do see more of the Latinx families [saying], "Oh is it because we got in a car accident when he was three and that's why he has autism?" Or "is it because I didn't breastfeed him?" You get a lot more of those trying to figure out what caused it questions.

Therapists primarily identified these themes as additional support for the need for accurate psychoeducation for parents.

Differing Perceptions of Parental Involvement

The discussion of perceptions and expectations about parents' role in the mental health treatment of their child, resulted in different responses by stakeholder group. Although variability existed, the majority of therapists reported wanting parents to be involved in their child mental health treatment but reported that they perceived that they were frequently working with parents who did not expect to have a role in their child's therapy. One therapist reported:

I think also they [parents] have experience with other therapists who only provide [therapy to the child only], and they're expecting that. And sometimes they [parents] don't have much communication with the therapist and they don't know what's going on [in treatment]"

When asked to identify potential differences between how the intervention process might differ between Latinx and non-Latinx white families, one therapist in the focus group responded:

I think where I might have seen a disparity, probably comes even a little bit sooner [in treatment] in terms of getting rationale and buy-in for why we're using some of these [parent training] strategies. I think some of the families that I've worked with were coming from a perspective, well, first they thought the intervention would be much more child focused, as opposed to having a larger parental focus. And so, kind of needing to

help them to understand why we needed to have such a large--why parental involvement was so essential.

In contrast, when parents were asked to respond to the question, “What do you think your role as a parent should be in your child’s therapy?” the majority of parents responded that they saw themselves have an active role in their child’s treatment. **During the interviews, 90% of parents stated that they expected to be highly involved in their child’s treatment.** The primary rationale that parents provided for participating in their child’s therapy was the need to learn new skills for themselves or as one parent described, “to learn, listen, understand, and practice in the therapy activities.” When asked about what a parent’s role in therapy should be, one parent stated, “Participate as much as possible and try to learn, take the opportunity to learn how to handle situations and how to deal with children and how to help them, because sometimes you don't know how to help them.”

In addition to learning new skills, parents also stated that they were motivated to participate in order to gain increased understanding of their child and the child’s diagnosis. One parent stated that participation helped her, “at certain times, to feel like him [son], to be able to understand him more” and another stated that therapy allowed her to “be in the shoes for my son to be able to understand it more.”

Despite therapists’ **perceptions** of a lack of **parental** interest or engagement, responses from parents suggest that, even when situational factors interfered, they still prioritized participation. The essential role of parents was clearly outlined by one mother who said,

Well, I think that the patients are important, but I think that most importantly are both the therapists and the parents. Because the therapists are the ones who impart the therapies and help them [the children] and us as parents also help the therapists by performing the

work at home... Because like I'm telling you, it's not so much-yes, I know that they're the ones [the children] who need the help, the attention and everything, but we are the ones who help them, the ones who are living everything for them.

Parent-Therapist Relationship: Influence of Respeto and Personalismo

The final theme **regarding the importance of the parent-therapist relationship and the factors that influence parent-therapist interactions** was an emergent theme identified by respondents and was not prompted by questions or interview prompts. Although exceptions existed, when therapists were asked to provide context for their relationships with the Latinx parents of their client, they most frequently brought up the concept of *respeto* as the theme that most significantly impacted their relationships, **with 76% of therapists endorsing this theme during focus groups**. Therapists noted that Latinx clients often did not speak up or ask questions of the providers in session due to cultural themes of deference to professionals. One therapist stated, “I do feel like it's particular to the Latinx culture ... [parents] don't really ask a lot of questions, present their understanding, or don't make a lot of comments.” Another commented, “I think there's a lot of respect for authority and not questioning authority. I think that's a big piece of it. Not knowing that they need to say something.”

Although the theme of *respeto* was identified by providers, it was not identified by parents **as an influence on the relationship**. The primary factors identified by parents as impacting parent-therapist relationships were themes of *personalismo* and *confianza*. Parents identified the importance of the development of *personalismo*, or a personal connection, with their child's therapist and made positive comments about therapists who presented with a warm and friendly demeanor and who expressed personal interest in their lives and the lives of their children. Similarly, the need for *confianza*, or the developmental of trust and a mutual respect,

was identified as an essential factor as evidenced by one parent's description of her relationship with her child's therapist:

We had a relationship of trust, it is as if I was talking with a friend, she made me feel as a friend, as someone who I could trust, as someone who listens to me and is not criticizing or watching to see what I'm going to say wrong or what I do wrong.

Parents repeatedly identified how the presence of *personalismo* and *confianza* influenced their own behaviors in treatment and impacted the relationship between themselves and the therapists; 86% of parents voiced recommendations for ways to improve the therapist-parent relationship. When asked about factors that would increase comfort and willingness of parents to engage and speak up in session, one parent stated:

I think that human quality, knowing that [the therapist] understands, give us the confidence to feel comfortable in asking [questions], knowing that he [therapist] as a professional also is sympathetic to what you are going through, that would help a lot.

Another parent stated, "Families need *confianza* not to feel ashamed of what happens in the session at times, of what the children do."

Conversely, parents were able to readily identify how the absence of these elements negatively impacted treatment. As one parent stated:

I think that the trust was a bit lacking. Maybe we felt the relationship between the therapist and us [parents] was a little cold, and sometimes that would inhibit us from being able to express to her what we may have felt or wanted in that moment.

In this instance, when asked what the therapist might have done to help address this lack of trust, the parent responded, "Perhaps show a little more of interest" again highlighting the importance of *personalismo*.

Discussion

Results from this study help shape our understanding of factors that influence mental health services for Latinx children with ASD by directly gathering stakeholder perspectives from both Latinx parent and providers. Overall, **the need for increased parental knowledge about ASD diagnosis and symptoms, differing perceptions between therapists and parents** regarding parents' role in treatment, and the importance of the parent-therapist relationship, **specifically the influences of *respeto*, *personalismo*, and *confianza*** were identified as primary themes. **These themes provide specific direction for enhancements to AIM HI to maximize engagement of Latinx families.**

The finding that Latinx families have limited knowledge and understanding of ASD **and experience self-blame about the onset of the disorder** are consistent with findings from previous research (Lopez, Xu, Magaña, & Guzman, 2018; Zuckerman et al., 2014), and highlight the importance of autism specific psychoeducation **as a critical component of any autism-specific intervention. Adding supplemental psychoeducation modules early in the treatment process and prior to implementation of intervention strategies can help mental health therapists adapt the pacing of the intervention as they allocate time to ensure parental understanding of ASD symptoms and the potential impact of these characteristics their child's behavior. Modification of intervention materials to ensure that content is "user friendly," culturally appropriate, and understood by families can also help address this need.**

The need for additional **and accurate psychoeducation about etiology** has been identified as a broader need for Latinx families (Perry, Hatton & Kendall, 2005; Yeh, Hough, McCabe, Lau & Garland, 2004). While parental self-blame about child mental health disorders is also evident in non-Latinx racial/ethnic groups (e.g., Harden, 2005; Moses, 2010), in Latinx parents, self-

blame has been negatively associated with education level (Fernández & Arcia, 2004). General (non-Latinx specific) strategies to address self-blame including facilitating self-compassion in parents (Neff & Faso, 2015) and redirecting blame to the physiological causes (Koro-Ljungberg & Bussing, 2009) are recommended; however, therapists should also be aware of the relationship between education level and feelings of causal responsibility in order to ensure that they are providing parents with less formal education, like those in our sample, with appropriately targeted psychoeducation. To help combat misinformation or the parental self-blame found in our study, Latinx parents of children with ASD may especially benefit from being explicitly told that while autism has a complex and not well understood etiology, parental behaviors do not cause autism.

When conceptualizing parents' need for psychoeducation, it is important to also recognize that parents' lack of available language about ASD may also reflect therapists' need for training in how to elicit this sensitive information from clients who may be different from themselves in both culture and education level. Therapists may benefit from increased training (provided in the context of EBP training) regarding fostering conversations about children's diagnoses with parents in a clear and culturally sensitive way that provides opportunities to facilitate conversations, encourages parents to voice their opinions, provides accurate psychoeducation, and sensitively challenge potential misappropriations of blame.

Across children's mental health, difficulties establishing parent engagement in treatment have been cited as barrier to EBP delivery across interventions and populations. In the current study, therapists' interpretation that Latinx parents have limited understanding of the need for parental involvement in therapy and less willingness to engage in treatment was dramatically different from Latinx parents' recognition of their critical role in their child's treatment and their

desire to participate in treatment and learn new skills. This discrepant finding is consistent with qualitative research conducted in an educational setting that found a similar pattern between teachers' and parents' perceptions of Latinx parents' involvement in their children's education. Although Latinx parents reported high academic expectations for their children and a desire to be more involved in their children's education, teachers perceived Latinx parents to be minimally involved and unreliable and to place a lower value on education. These discrepancies in perceptions caused many Latinx parents to feel excluded from their child's school community (Quiocho & Daoud, 2006).

The differing perceptions regarding the expectations for parent involvement in treatment is an important finding from the current study that appear to be related to the Latinx cultural values of *personalismo*, *confianza*, and *respeto*, which likely interact to influence engagement (Anez, Silva, Paris & Bedregal, 2008; Barker, Cook & Borrego, 2010). *Respeto* is a cultural value that is displayed across several domains, including obedience to authority, deference, decorum, and public behavior (Calzada, Fernández, & Cortés, 2010). While there is debate about the impact of *respeto* on therapeutic interactions, as the value encompasses deference to authority figures, such as a mental health professional, a client who identifies with *respeto* may refrain from openly expressing his or her own opinions (Anez et al., 2008). Though *respeto* has been identified as a potentially protective factor in treatment retention (e.g., Kim, Lau & Chorpita, 2016), therapists may be misinterpreting in-session behavioral deference as lack of engagement or minimization of parental role in treatment. Latinx parents' desire for *personalismo* and *confianza* and the preference for caring, personal interactions with a mental health providers is consistent with previous findings (Callejas, Hernandez, Nesman, & Mowery, 2010; Umpierre et al., 2015) and suggests that, many Latinx parents who want to be actively

involved in their child's therapy, may not develop the necessary trust to do so unless they perceive that the therapist genuinely cares about them and their child. This initial reticence from parents, which may be the result of lack of *confianza* or rapport with the therapist, may be incorrectly interpreted by the therapists as a lack of interest of the parents in participation or their unwillingness to engage. **These inaccurate perceptions are important to recognize and correct as they have the potential to create self-fulfilling cycles, in which therapists' low expectations cause Latinx parents to feel unwelcome or excluded and subsequently result in reduced parent engagement in their child's mental health treatment.**

The clear message from parents, and a way to overcome these misinterpretations, is that some therapists need to recognize that they must do more to develop the relationship aspects of the therapeutic alliance and build trust between parent and therapist. This is consistent with Matos and colleagues' (2006) qualitative study in which parents recommended that therapists spend more time at the beginning of each session conversing with parents and engaging in social interactions. Using strategies such as the *la plática* (small talk) technique (Magaña, 2000; Valle & Mendoza, 1978), acknowledging personal details about the family in session (e.g., asking about a recent birthday party), or sharing some personal information or experiences with the parent are all ways therapists can try to establish *personalismo*. In therapeutic terms, these results highlight the need for providers to slow the pace, particularly during initial treatment sessions and take time to build rapport. Given that evidenced based treatment models often have prescribed content and pacing for sessions, additional training for providers regarding how to adapt to address cultural values in treatment, specifically in the context of structured protocols, will be required.

Recognizing the dynamic interaction between these cultural values may help mental health professionals foster engagement and alliance in more effective ways. For example, strategies such as *la plática* designed to promote *personalismo* and *confianza* may also indirectly impact the deferential components of *respeto* by allowing parents to see the therapists less as authority figures requiring deference, which may increase their willingness to speak up and engage in sessions. This hypothesis is consistent with previous findings from Cortes and colleagues in the study of an intervention designed to teach skills in question formulation to increase participation in mental health services. The authors note that for some Latinx participants viewing their mental health provider as a “friend” developed trust and support between the client and therapist and encouraged clients to more actively participate in their own treatment (Cortes, Mulvaney-Day, Fortuna, Reinfeld, & Alegría, 2009). *Personalismo* and *confianza* can also facilitate conversations, in which the therapist and parent openly communicate their expectations of treatment. Literature has shown that misaligned expectations (e.g., timeline of treatment progress, best parenting practices) can result in treatment attrition (McCabe, 2002). Not surprisingly, considerations about client trust and therapist-initiated conversations about treatment expectations are built into cultural adaptation frameworks like the Ecological Validity Model (Domenech Rodríguez, Baumann & Schwartz, 2011). In one study outlining the cultural adaptation of a parent training program, recommendations state that therapist should not only engage in increased efforts to build rapport with Latinx parents, but they should also elicit complaints from parents who display deference (McCabe et al., 2005) in an effort to prevent deference associated with the value of *respeto* from precluding treatment engagement. The likelihood for interplay between these cultural values suggests the presence of dynamic interactions that need to be carefully considered by therapists.

Given the multiple studies outlining barriers to Latinx's families accessing mental health services (Alegría, Green, McLaughlin & Loder, 2015; Kapke & Gerdes, 2016; McCabe, 2002; Young & Rabiner, 2015) and high treatment attrition in ethnic minority groups (Barrett, Chua, Crits-Christoph, Gibbons & Thompson 2008; Kazdin, Stolar & Marciano, 1995; Kazdin, Holland & Crowley, 1997; Miller, Southam-Gerow & Allin, 2008), it is essential to facilitate engagement using culturally-appropriate approaches for those *in* treatment. As the majority (65%) of the therapists in our sample did not identify with being Latinx, it is possible that cultural incongruence, indexed via ethnic match between therapist and client, may have contributed to therapists' misinterpretations of Latinx parents' in-session behaviors. Some studies show that provider-client matching by native language and ethnicity is linked to a higher likelihood of clients staying in and being satisfied with treatment (Campbell & Alexander, 2002; Sue, 1998). Though consumers may prefer a therapist of their same ethnic or cultural background (Cabral & Smith, 2011), the culturally sensitive strategy of matching by ethnicity (Ibaraki & Hall, 2014) is not always feasible in community mental health services, which highlights the need for all providers to approach therapeutic interactions from a perspective of cultural humility.

Therapist self-reflection and recognition of their own limitations and their potential to misunderstand and misinterpret client behavior is essential and requires providers to shift to an approach of cultural humility (Tervalon & Murray-Garcia, 1998), a framework driven by provider humility, self-reflection, and self-critique. Cultural humility asks providers to be critically self-aware, recognize their own limitations, examine the inherent power dynamics that are present in a provider-client relationship, and recognize and respond to system level barriers (Fisher-Borne, Montana Cain, & Martin, 2014). The recognition of the need for training in cultural humility has been growing across disciplines and there have been increasing calls for

training in cultural humility to be a critical aspect of training for healthcare providers (Cruess, Cruess, & Steinhart, 2010).

Limitations

Our study sample consisted of Latinx parents drawn from a region in Southern California and, as such may not be representative of views of Latinx parents from other geographic locations. Related, families in the current study were receiving services through publicly funded mental health programs and their perspectives on their child's mental health treatment may have been influenced by the context on which the treatment was received and perspectives reported here may not be shared by Latinx families in mental health treatment in service settings with a broader range of funding types. Research is limited in that perspectives are gathered only from participants who agree to participate. All therapist and parent participants in this study participated in both a large-scale community effectiveness trial of a mental health intervention, as well as the supplemental data collection that was used for the current study and their views may differ from perspectives of parents or providers who declined opportunities to participate. Finally, while findings explored in the current study reflect the primary themes identified in the data, it is not exhaustive and important topics continue to require future study and targeted recommendations for intervention. For example, in the current study, some therapists referenced Latinx parents with inaccurate, and potentially self-blaming, understandings of their child's ASD diagnosis; however, this topic was not explored in detail in the current study. Future study of this topic has the potential to offer valuable insight into Latinx parents' understanding of their child's disorder as well as produce valuable recommendations for developing corrective psychoeducational interventions for Latinx caregivers with children diagnosed with ASD.

Implications

Overall, this study has provided important lessons that provide specific direction for adaptations to the AIM HI intervention and have broader implications for intervention development and community implementation including systematic refinement of EBPs to facilitate fit and sustained implementation.

One important reminder from these findings is the importance of gathering perspectives from multiple stakeholders when implementing interventions, both on a program and an individual scale. It is informative to remember that perspectives of parents and therapists may at times differ, resulting in different expectations and, at times inaccurate assumptions. Clinicians implementing EBP interventions are encouraged to directly gather and discuss the perspectives of their clients and their families throughout treatment, as well as self-reflect on their own beliefs and expectations, **using a framework of cultural humility**, to facilitate recognition and correction of any potentially inaccurate assumptions that may impact treatment.

This study offers support to the growing recognition that, in mental health services for Latinx families, relationship building is essential and takes time. Awareness of the critical role of the parent-therapist relationships and the need to attend to this relationship in order to successfully meet the needs of their child clients is essential for mental health providers working with this population. **Intervention training models, especially those for interventions targeting Latinx youth, should include explicit training promoting collaborative engagement with parents and other caregivers and should provide explicit guidance about how to adapt structured protocols, particularly the pacing of implementation, to address cultural values and needs.**

Based on these findings, the next steps in this line of research are to develop and test the a toolkit targeting both parents and providers to enhance delivery of the AIM HI intervention. The planned AIM HI *Educativa* toolkit is designed to increase parent understanding of an ASD

diagnosis and knowledge about their role in their child's mental health services and increase therapist confidence and competence delivering AIM HI to parents from diverse cultural backgrounds and/ or with limited English proficiency. Online psychoeducation materials for providers will be adapted and pilot tested based on the Parents Taking Action (Magaña, Lopez, de Sayu, & Miranda, 2014) psychoeducation intervention and provider training module and will focus on helping providers learn to individualize AIM HI based on cultural norms and values, modify the pacing and language of the intervention to ensure parent understanding, and understand the impact of parent and provider cultural values on parent engagement and the development of the therapeutic relationship. Parent materials will focus on increasing psychoeducation about autism, promoting active parent participation and collaborative engagement in sessions, and exploring stigma and dispelling myths about ASD. All materials from the toolkit will be specifically adapted for use in evidence-based interventions and training will be provided to help therapists learn to successfully integrate elements of the AIM HI *Educativa* Toolkit into existing structured interventions.

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