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Article

# Parent Mediated Autism Intervention through a Culturally Informed Lens: Parents Taking Action and Pivotal Response Training with Latine Families

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**Abstract: Background/Objectives:** The prevalence of autism has increased substantially among Latine children, however, few service systems are prepared to provide culturally relevant services. Parents Taking Action (PTA), is a culturally informed parent-mediated psychoeducation program designed to meet the informational needs of Latine families of children with autism. The purpose of this study was to pilot a hybrid model of intervention by including direct parent coaching through pivotal response training (PRT) along with PTA among Latina mothers of children with autism; **Methods:** Ten Latina mothers of children 8 and under with autism participated in this study. Mothers received PTA from two bilingual trained promotoras (community health workers). PTA included 14 2-hour psychoeducation sessions. Mothers also received 4 one-hour sessions of PRT from bilingual/bicultural coaches; **Results:** Paired samples t-tests indicated significant increases in family outcomes, self-efficacy in using the intervention strategies, and frequency of using strategies, from pre to posttest; **Conclusions:** This study suggests that culturally informed parent-mediated autism intervention coupled with parent coaching positively affects family outcomes among Latine families of children with autism.

**Keywords:** autism ; Latine ; families; intervention; culturally informed

## 1. Introduction

Autism prevalence has multiplied exponentially, affecting 1 in 36 children or .8% of the population [1]. Improved identification of autism has occurred among 4- and 8-year-old non-white children [1, 2, 3]. In 2020, for the first time since the CDC collected prevalence data, more 8-year-old Black, Latine, and Asian or Pacific Islander children were identified with autism than White children. While improved identification of autism is necessary, early diagnosis is also critical for optimizing support to individuals with autism and their families [4]. Despite the increase in prevalence, Latine children continue to be diagnosed later than non-Latine white children [5, 6]. Latine children more often receive a diagnosis of speech impairment over autism when intellectual disability is also present [7]. Many Latine children diagnosed with autism receive inadequate quality of care and have unmet service needs [6,8,9].

Various intersecting sociocultural factors at the child, parent, provider, community, and policy levels create and enhance barriers to autism diagnostic and treatment services among Latine children [10]. Researchers have underscored the importance of including culture, innovation, and exploratory methods when developing and implementing interventions for culturally and linguistically diverse families [11, 12]. Parents Taking Action (PTA) is a unique and culturally informed psychoeducation program developed with the needs of Latine families raising children with autism integrated throughout the curriculum and program delivery. PTA has been shown to meet the informational needs of Latine families of children with autism, enhance parents' skills to work on their children's social communication, and ability to advocate for treatment services [6].

However, PTA is a didactic program that does not include direct practice of strategies with children and parents. Thus, an objective of this study was to expand the parameters of the PTA program by including direct coaching with parents and children through a form of evidenced-based practice, Pivotal response training (PRT). PRT is a form of applied behavior analysis targeting

functional and social communication skills by utilizing the natural environment to motivate children with autism [13]. Given the flexibility of PRT, it aligns with core dimensions of PTA that include flexibility, collaborative goal planning with parents, and inclusion of the child's natural environment. Further, the evidence-based communication, social, and behavior management strategies taught in PTA are also featured in PRT, allowing for streamlined practice. The objective of this study was to pilot a PTA and PRT intervention targeting the use of evidence-based social communication intervention strategies among Latine families of children with autism.

### *1.1. Latine Children with Autism*

### *1.2. Parents Taking Action*

### *1.3. Pivotal Response Training*

### *1.4. Research Question and Hypotheses*

## **2. Materials and Methods**

Given the pilot nature of this study, all eligible participants were offered the program after meeting study eligibility. Mothers received 14 2-hour sessions of the PTA program in their homes, from two promotoras (community healthcare workers). PTA content covers general information about autism, treatment services, advocacy, self-care, and strategies to enhance children's social communication. PTA is a didactic program that required mothers to follow a participant manual, while promotoras utilized a promotora manual to guide them through the informational material. Video examples and audio materials were also included as adult teaching strategies. Promotoras provided participants with a supplementary resource guide about local autism and general resources for evidenced based treatment as well as guides for navigating services. If a parent needed additional supports not found in the guide the promotora communicate with the study director who coordinated with social work interns to identify possible external resources.

Mothers also received 4 one-hour sessions of pivotal response training (PRT) from bilingual/bicultural coaches. The PRT coaches were undergraduate and graduate students who completed training in PRT by a certified PRT trainer at a local autism service organization. The trainer provided feedback to the coaches before they delivered PRT to mothers in the study. The one-hour PRT sessions were delivered immediately after four corresponding PTA sessions that focused on teaching mothers evidence-based skills to work with their children on social communication and behavior management (i.e., Play Together, Learn Together Creating Everyday Opportunities to Encourage Communication; Challenging Behavior is Communication; Making Challenging Behaviors Less Likely and Responding Appropriately When They Do Happen). The promotoras and PRT providers interacted to confirm information about meeting with mothers. However, the study coordinator served as a liaison to avoid confusion about ease communication. The skills-based sessions of PTA were session 7, 8, 10, and 11. Once a promotora completed session 7, they would contact the study coordinator to debrief. Promotoras would also inform the coordinator about the best time/day for the mother to meet. The study coordinator would then contact the PRT provider to let them know it was time to schedule the mother for a PRT session.

All intervention materials were offered in Spanish and English. Mothers were asked to choose which language they preferred to receive the intervention. Of the ten who started the intervention four requested the entire program be delivered in Spanish. The remaining mothers requested the program in English. The intervention package was delivered in the homes of the mothers. Children were only required to be present for the PRT sessions.

Mothers completed questionnaires regarding child, parent, and family outcomes pre-intervention, post-intervention after completing all PTA/PRT intervention sessions, and follow-up. Ten minutes of parent-child interaction were audio-visual recorded at these time points, if mothers agreed to the taping. After all participants completed the intervention focus groups were conducted

in Spanish and English to assess for the feasibility of the intervention. Four mothers participated in the focus groups (two in Spanish, two in English).

### 2.1. Participants

Ten Latina mothers of children diagnosed with autism were recruited for participation. To participate, mothers were required to identify as Latina and have a child diagnosed or at-risk for autism. Mothers were not required to be immigrants. Children were required to be 8 years of age or under. Individuals who did not meet these criteria were not included in the study. Participants were recruited through local Spanish language support groups for families of children with autism and/or other developmental disabilities, autism service agencies, and autism support groups. Mothers were offered \$20 per assessment (baseline, post-intervention, follow-up, focus group) for their participation. A previously established advisory board comprised of autism, cultural, parent, and community stakeholders provided recruitment method suggestions. Due to the attrition of three mothers, this study includes data from the seven mothers who completed all study components. The majority (71.4%) of children were male. Children ranged 2 to 7 years of age. Other demographic information is available in Table 1.

**Table 1.** Sample Demographics of Participants at Baseline.

Baseline characteristic	N <sup>1</sup>	%
Mother		
Mean age in years ( <i>SD</i> )	38.57 (8.44)	
Married or living together	6	85.7
Level of education		
Less than high school	1	14.3
High school	2	28.6
Any post-secondary education	4	57.1
Annual household income		
\$60,000 or more	1	14.3
\$30,000-59,999	2	28.6
\$29,999 or less	1	14.3
missing	3	42.9
Employed part-time	3	42.9
Foreign born	5	71.4
Good/Excellent health	6	85.7
Child		
Mean age in years ( <i>SD</i> )	3.57 (1.62)	
Male	5	71.4
CARS severity		
Minimal to no symptoms	--	
Mild to moderate	6	85.7
Severe	1	14.3

<sup>1</sup>N=14; mothers n=7, children n=7.

### 2.2. Measures

Demographic and Health Questionnaire regarding the child (i.e., age, age of diagnosis, etc.) and mother (i.e., age, annual income, employment, education, general health, etc.) was completed during the baseline visit.

Childhood Autism Rating Scale, 2nd edition (CARS2-ST; [36]) was utilized at the baseline assessment to determine autism severity among children in the study. The CARS2-ST is a 15-item autism assessment tool designed to be used following direct observation of a child. In this study, children were observed for 15 minutes, after which a trained researcher completed the assessment tool. Each item is rated between 1) within normal limits for that age to 4) severely abnormal for that age. The raw scores are then summed for a total score. Cutoff scores for autism vary by age. However, the overall cutoff score is 28. Scores can be further categorized into three severity groups, “minimal-to- no symptoms”, “mild-to-moderate symptoms”, and “severe symptoms”. The CARS2-ST has been used across a wide range of children.

Social Communication Questionnaire (SCQ; [37]) current form was used to determine children’s degree of social communication skills. The SCQ was utilized at each assessment time point. Participants were offered both the English and previously translated Spanish version to complete. The SCQ includes 40 “yes” or “no” items, such as “Does he/she ever talk with you just to be friendly (rather than to get something)?” or “Does he/she respond positively when another child approaches her/him?”. The total number of Yes responses are summed for a total social communication score. Lower scores indicate less social communication impairment. Mothers were asked to complete this form during the pre, post, and follow-up data collection points.

Family Outcome Survey (FOS; [38]) was developed by the Early Childhood Outcomes Center with support from the Office of Special Education Programs, U.S. Department of Education. The 24-item measure was developed to assess five areas of early intervention program support, 1) understanding your child’s strengths, needs, and abilities, 2) knowing your rights and advocating for your child, 3) helping your child develop and learn, 4) having support systems, 5) accessing the community. Responses range on a Likert scale from 1) not at all to 5) completely. Sample items include, “We know who to contact and what to do when we have questions or concerns.” and “We are able to talk with other families who have a child with similar needs.”. The FOS has been translated to Spanish previously. The FOS was completed at baseline, post-intervention, and follow-up time points.

Self-Efficacy of Using Strategies Eleven items assessed the level of confidence mothers felt using the evidence-based (EB) strategies they learned during the intervention program. This scale was developed by the original PTA research group and translated to Spanish. Efficacy items were anchored by the phrase, “I feel confident...”, with response options ranging on a Likert scale from 1) completely disagree to 4) completely agree. Sample items include “I feel confident modeling for my child what I want him/her to do” and “I feel confident using social stories”. Responses were summed for a total efficacy in use of strategies score.

Frequency of Using Strategies To determine the frequency to which mothers utilized the EB strategies, mothers were asked how often they used 14 EB strategies. As with the efficacy scale, this measure was developed by the original PTA research group and translated to Spanish. Sample items include, “How often have you tried to make learning fun by incorporating your child’s favorite materials, activities, and interests?” and “How often have you used a token economy to reward appropriate behavior?”. Response options for 14 EB strategies ranged on a Likert scale from 1) Never to 4) Always. To calculate a total frequency of using strategies score all responses were added, with greater scores indicating more frequency of use.

### 2.3. Data Analysis

The subscales for each dependent variable were calculated and data analyzed using SPSS 28. Paired sample t-tests were completed to compare baseline and post-intervention scores for changes in family outcomes, mothers’ efficacy in using the strategies, and frequency of using the strategies among the seven mother-child dyads that had complete data for both timepoints. The data was normally distributed, and no missing data was observed for the variables of interest included in the present study. *Cohen’s d* was calculated using the G\*Power tool for Windows to account for the within-subjects design [39].

### 3. Results

#### 3.1. Parent Variables

The paired samples t-tests showed significant differences in three family outcomes pre- vs. post-intervention for understanding their child's strengths, needs, and abilities ( $10.29 \pm 3.20$  vs.  $13.00 \pm 2.31$ ,  $p < .05$ ,  $d = 1.26$ ), knowing their rights and advocating for their children ( $10.00 \pm 5.20$  vs.  $17.29 \pm 2.81$ ,  $p < .05$ ,  $d = 1.51$ ), having a support system ( $11.43 \pm 5.26$  vs.  $17.86 \pm 2.41$ ,  $p < .05$ ,  $d = 1.37$ ) and total family outcome scores ( $48.00 \pm 16.02$  vs.  $65.14 \pm 7.24$ ,  $p < .05$ ,  $d = 1.14$ ) (Table 2). Paired samples t-tests indicated that mothers' report of efficacy using the EB strategies differed significantly pre- vs. post-intervention ( $34.43 \pm 3.21$  vs.  $42.14 \pm 3.24$ ,  $p < .05$ ,  $d = 1.52$ ). The frequency to which mothers used the EB strategies was also significantly different pre- vs. post-intervention ( $36.57 \pm 3.41$  vs.  $46.29 \pm 4.61$ ,  $p < .05$ ,  $d = 1.59$ ) (Table 2). The effect size for each of these significant results was large.

**Table 2.** Paired Sample T-tests.

	Pre <sup>1</sup>		Post <sup>1</sup>		t(7)	p	Cohen's d
	M	SD	M	SD			
Understand child's strengths, needs, and abilities	10.29	3.20	13.00	2.31	-3.36	.02	1.26
Know your rights and advocate for your child	10.00	5.20	17.29	2.81	-3.43	.01	1.51
Help your child develop and learn	10.14	4.60	13.71	1.89	-1.99	.09	.75
Have a support system	11.43	5.26	17.86	2.41	-3.63	.01	1.37
Access the community	17.57	4.54	21.14	2.85	-1.66	.15	.63
Total family outcomes	48.00	16.02	65.14	7.24	-3.00	.02	1.14
Efficacy in the use of evidence-based strategies	34.43	3.21	42.14	3.24	-4.04	.01	1.52
Frequency using evidence-based strategies	36.57	3.41	46.29	4.61	-4.21	.01	1.59

<sup>1</sup>N = 7.

#### 3.2. Child Variables

To determine change in child outcomes from baseline and post-intervention children's SCQ social communication scores and the number of services children received were tested with paired samples t-tests. No significant differences were found for either social communication scores or the number of services children received pre- vs. post-intervention.

### 4. Discussion

The intersection of the growth of the Latine population and the amplified prevalence of autism has heightened attention on the persistent disparities in the diagnosis and treatment of Latine children with autism. Researchers have called for the development and implementation of exploratory and innovative interventions to meet the needs of culturally diverse families [11,25]. The present study answered the call by investigating a culturally informed psychoeducation program, PTA, for Latine parents of children with autism and extended the impact by combining it with PRT,

an evidence-based intervention based on applied behavior analysis. Prior studies of PTA have found that parents desired direct coaching and feedback on the use of EB strategies with their children in addition to the original didactic design of the PTA program [26]. In addition, previous research indicates that Latine families are likely to not receive coaching from early intervention service providers based on cultural and linguistic factors as well as other provider-perceived barriers [16]. After carefully considering multiple models, PRT offered a fitting model of evidence-based practice for several reasons. First, PRT has been identified as a parent training intervention for parents of children with autism [32]. Second, PRT has previously been used with racial/ethnic diverse families [33,34]. Third, PRT includes similar methods and strategies to improve children's social communication as found in PTA such as utilizing the natural environment, utilizes everyday routines for skills practice, and engages parents in collaborative goal planning [32]. Thus, the PTA/PRT intervention tested in this study combined two previously established evidence-based interventions to determine whether it could meet the informational and skill development needs of Latine parents of children with autism.

Ten Latina mothers and their children with autism participated in this study. All families were provided the PTA/PRT intervention in their homes. Two bilingual, Latina mothers of children with developmental disabilities were trained as promotoras to deliver the PTA program. Two bilingual/bicultural Latina graduate students were trained to deliver PRT. Parent and child assessments were conducted at baseline, post-intervention, follow-up. Seven mothers completed the entire intervention protocol and all three assessments. Four mothers participated in focus groups about the feasibility of the intervention. Two mothers left the study due to other family needs that interfered with their ability to complete the intervention or the program fit. One mother reported that there were too many interventions her child was in to keep track of. Another mother stated that she did not want to complete more forms. The third mother decided the intervention was not an appropriate fit for her needs after completing several sessions of PTA.

Study findings indicated that after receiving the intervention, compared to baseline, mothers had significant increases in understanding of their children's strengths, needs, and abilities, knowledge of their rights and how to advocate for their children, as well as an improved understanding of their support system. Lastly, family outcomes significantly increased from baseline to post-intervention. Increased family outcomes are linked to greater buy-in effectiveness of parent-mediated interventions in community settings [40]. These findings suggest that the PTA/PRT intervention has the potential to fill the informational gap for Latine families raising children with autism. These results mimic previous research finding that PTA positively impacted family outcomes from pre to post intervention [27,41].

The findings indicated that the PTA/PRT intervention had a positive impact on Latina mothers' efficacy in using the evidence-based intervention strategies with their children from pre- to post-intervention. Parental self-efficacy has been identified as an essential element in parent-mediated intervention for children with autism given the correlation it has to parent stress, family outcomes, the degree to which parents are involved in their children's intervention, and parents' ability to be successful with the implementation of intervention strategies [42]. Thus, the efficacy changes in the present study have broader implications for the impact of the PTA/PRT intervention. For instance, parents of children with autism who have increases in their self-efficacy are more involved in their children's therapy and are more satisfied with their treatment [43]. Lastly, it is possible that enhancing mothers' efficacy may have implications for mothers' ability to advocate for their children [19].

Lastly, the study findings demonstrated that mothers increased the frequency of using the evidence-based strategies from pre- to post-intervention. Both PTA and PRT principles support parents' use of the evidence-based strategies by encouraging them to implement them in everyday settings with their children. According to Kashinath et al. [44] parents who perceive embedding strategies into daily routines are likely to use them more often and find them useful to support their children's social communication. The self-reported increases in the efficacy and frequency of using the evidenced-based strategies that mothers reported suggest mothers were active participants in the intervention, learned important skills to enhance their children's social communication and were

willing to use them with their children after receiving the PTA/PRT intervention. Thus, not only did this study offer a unique, culturally informed model of intervention that fills the informational gaps of Latine families raising children with autism, but also enhanced their efficacy and skill development needs to support their children's social communication with evidence-based strategies.

The social validity of the intervention was determined by the solicitation of feedback about the intervention, including experiences with the promotoras and PRT coaches. Mothers shared positive responses about the intervention including their satisfaction with the location of the intervention, information about autism and advocacy, interactions with the promotoras and PRT coaches, naturalistic strategies featured in the intervention, and flexibility of the program scheduling. The area of dissatisfaction was with the videos featured in the PTA materials. PTA includes audio and videos in select sessions to demonstrate content. However, technical difficulties disrupted the flow of play at times. The mothers indicated frustration with such disruptions and suggested new videos or simply reading the content from the manual instead of trying to watch the video. Mothers also reported that it would have been helpful to streamline the PTA and PRT content within the manual. This information was especially helpful to the research team as we work to enhance the intervention manuals for future use. Overall, mothers emphasized that they and their children benefited from the PTA/PRT intervention and would recommend the program to other Latine families.

#### *4.1. Limitations*

There are several limitations to this promising pilot study that require discussion. First, the generalizability of the study is limited by the small sample size. However, the effect sizes of the results indicate a large effect that holds statistical and clinical significance. Second, the absence of a control group does not allow for specific determinations about whether it was the intervention itself that led to the changes in the baseline to post-intervention ratings across the various parent and family outcomes. Third, all parent measures were self-report, which may have been affected by social desirability. The focus group data may reflect social desirability. An anonymous survey may provide less biased feedback about how mothers experienced and liked/disliked the intervention program. The parent-report nature of the SCQ may also have limited our ability to detect difference in children's social communication. Furthermore, based on the data collection methods and analyses there is no way to determine which effects reported in this study are specifically linked to PTA vs PRT. Finally, we focused the present study on the pre and post data only. We plan to develop a future paper to analyze the follow-up data and suggest other researchers include follow-up measures of parent and child outcomes in their own work.

#### *4.2. Implications for Practice*

The study offers several implications for practice with Latine families of children with autism. Given that the delivery mode utilized promotoras de salud, the study demonstrated an opportunity to formally integrate the Latine community into autism practice. The promotora model is a cost-efficient approach to informing Latina mothers about their children's autism and how to navigate service systems. By providing the promotoras with formal training their own leadership capacity was developed, enhancing their opportunities for career advancement and abilities to support their own children. This by-product of the intervention model has been demonstrated in other studies utilizing a promotora de salud model [45]. The positive reception of PRT as the ABA framework by the mothers in the study suggests that PRT is an acceptable evidence-based treatment among Latina mothers. The naturalistic and individualized elements of PRT allowed for it to be embedded within the cultural context of the participants and PTA content while advancing the use of evidence-based practice. Further, integrating PTA and PRT extended the participants' opportunity to practice skills to enhance their children's social communication and receive direct feedback about their skills growth. Although early intervention programs within Part C of IDEA offer coaching elements, a recent study found that many early interventionists report not providing coaching to linguistic and cultural minority families [31]. Specifically recruiting bilingual/bicultural students to train to deliver the PRT coaching alleviated several barriers to service delivery that saturate early intervention

programs in community settings [30,31]. By combining the promotora model of PTA with PRT policymakers can optimize various treatment reimbursement systems to cover the cost of care.

#### *4.3. Implications for School Age and Beyond*

The present study offers implications for autistic Latine children throughout their lifespan and families. Recently, PTA has been growing in use with adolescents and the transition to adulthood population. For instance, Garcia Torres et al. [46] adapted PTA for youth age 10 to 17 and their parents in Bogota, Colombia. To meet the needs of parents of pre-adolescents and adolescents the topics of sexuality and adolescence were included in the youth-focused PTA program, Padres Unidos en Transformación y Empoderamiento (PUENTE) was developed based on PTA in San Diego, CA for 11 to 16-year-old Latine with developmental disabilities [47]. In PUENTE topics expanded to developmental milestones within peer relationships and independence across daily living skills. Parents were also provided information about services aligned for 11 to 16-year-old youth in their regions. Both adaptations of PTA for youth were found to positively impact outcomes in knowledge about autism, connecting families with community support, and skill mastery among Latine parents post-intervention, demonstrating the utility of core elements of PTA with Latine adolescents and their families.

#### *4.4. Implications for Future Research*

Despite the small sample size, the study offers insight for testing the intervention with a larger, more heterogeneous sample of Latine children and families. A randomized control trial of the intervention, including a PTA group, would help to parcel out the effect of PRT separate from PTA on parent outcomes. Moreover, future directions should seek to include direct measures of children's social communication. It is possible that a more precise measure such as weekly recordings of children may reveal important changes in their social communication. Similarly, adding a weekly recording of the mother-child dyad engaging in play activities could reveal more nuanced information about how mothers' skill set working with their children changes over time. A more objective measure of feasibility or participant satisfaction beyond focus groups would provide valuable information about the feasibility of the intervention. It would be insightful to gather data about the professional development enhancements of the promotoras throughout their employment on the intervention and beyond. For instance, whether promotoras added more hours of training to their experience, joined support groups, were offered and/or accepted other employment opportunities, etc. The same information could be gathered for those taking on the role of PRT coaches. Such information would be helpful to understand the larger community impact and sustainability of the intervention [44]. Lastly, the lack of changes in the number of treatment services children received from pre- to post-intervention may reflect the challenges Latine families encounter as they navigate the Arizona early intervention and department of developmental disabilities systems. Rather than a failure of the study intervention, this finding may be indicative of systemic issues in need of change. To determine this, future research will need to compare findings in service access across various states. For instance, Zeng et al. [28] found site differences in services received from pre to post intervention, comparing the effects of PTA in states with different autism service delivery systems. The authors suggested that state level differences may have impacted the degree to which participants could utilize the advocacy skills learned in PTA to increase the number of services children were able to receive.

### **5. Conclusions**

The present study provided the findings of a pilot intervention study of Parents Taking Action combined with Pivotal Response Training among Latine children with autism and their families. The findings revealed that the seven mothers who received the PTA/PRT intervention had significant increases in understanding their children's developmental needs, knowledge of how to advocate for them, understanding of their rights, and awareness of their support system, after completing the PTA/PRT intervention. Mothers also reported greater efficacy in the use of evidence-based strategies

and greater frequency of using the evidenced-based strategies post-intervention. These findings emphasize the utility of an exploratory and innovative intervention for Latine children with autism and their families. This paper contributes to the knowledge base on family support interventions responsive to the increasingly culturally and linguistically diverse environments in which individuals with intellectual and developmental disabilities, particularly autism live.

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**Institutional Review Board Statement:** “The study was conducted in accordance with the Declaration of Helsinki, and approved by the Institutional Review Board of ARIZONA STATE UNIVERSITY INSTITUTE (STUDY00007377 and 11/27/17 for the intervention; STUDY00020719 and 9/20/24 for data analysis).” for studies involving humans. ”.

**Informed Consent Statement:** Informed consent was obtained from all parents involved in the study. Informed consent was obtained from all parents for child participants.

**Data Availability Statement:** The data presented in this study are available on request from the corresponding author due to Institutional Review Board guidelines.

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**Conflicts of Interest:** The authors declare no conflicts of interest.

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