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Support Group on Neurodivergent Affirming Care for Spanish-Speaking Caregivers

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Support Group on Neurodivergent Affirming Care for Spanish-Speaking Caregivers

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CAPSTONE FINAL PAPER APPROVAL FORM

The Capstone Final Paper is the final product that the OTD students need to complete to report his/her Capstone Project and his/her Capstone Experience.

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We, the undersigned, recommend that the Capstone Final Paper completed by the student listed above, in partial fulfillment of the degree requirements, be accepted by the Georgia State University.

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Abstract

This study addresses the unique challenges faced by Spanish-speaking families with neurodivergent children in accessing culturally relevant support and guidance. Recognizing the barriers posed by language, limited resources, and cultural differences, the study aims to culturally adapt a parent training group curriculum to enhance accessibility and availability of support. The purpose is to empower parents, reduce stress, and improve the overall well-being of both parents and children through culturally tailored interventions. Methods involved a needs assessment through interviews with experienced occupational therapists and surveys with Spanish-speaking parents, leading to the adaptation of the curriculum and virtual group sessions facilitated by a Spanish-fluent therapist. While preliminary results showed a decrease in reported stress levels post-workshop, the small sample size limited statistical significance. Nonetheless, the study highlights the potential benefits of parent group training workshops in addressing parental stress and fostering caregiver confidence. The experiences of Spanish-speaking caregivers highlight the importance of cultural sensitivity in supporting families and advocating for acceptance, emphasizing the need for more inclusive and culturally sensitive parent support services to improve outcomes for neurodivergent children and their families.

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Summary

Background: Caregivers of children with neurodivergencies often face significant stressors, and those from culturally diverse backgrounds may encounter additional stressors linked to their cultural beliefs and traditions not being reflected in recommendations for care and support. These challenges include communication barriers, a lack of understanding of neurodivergent differences, attitudes toward disability, and limited access to culturally relevant resources (Baunmann et al., 2015). Parent training groups can serve as a valuable resource for parents, providing them with guidance and support when needed. Unfortunately, these groups often cater primarily to the typical American family, resulting in the oversight of diverse populations, particularly the Hispanic community, which can benefit from culturally appropriate parent training support. Occupational therapists and other professionals from different disciplines should take these parents' wants and needs into consideration to ensure the success of their child's development and enhance their personal well-being. Spanish-speaking families with neurodivergent children often face unique challenges in accessing culturally appropriate support and guidance. Language barriers, limited resources, and cultural differences can hinder their ability to navigate the complexities of raising a child with neurodevelopmental difficulties. Recognizing these challenges, this study aims to culturally adapt a parent training group curriculum to improve the accessibility and availability of support for Spanish-speaking families.

Purpose of Capstone: The purpose of this study is to culturally adapt a parent training group curriculum and assess its effectiveness in providing guidance and support to Spanish-speaking families with neurodivergent children. The outcome of this study will provide evidence on whether a culturally tailored intervention can empower caregivers, reduce stress, and enhance the overall well-being of both caregivers and children.

Learning Objectives:

1. To develop an understanding on the efficacy of a parent training group through program curriculum and evaluation.
2. To demonstrate understanding of the needs of Hispanic caregivers of children with neurodivergencies within appropriate cultural context.
3. To identify strategies that will support parents to better understand their child and their neurodivergent differences.

Output: The output of this capstone project is a written article, focusing on the effectiveness of culturally relevant parent training support for caregivers of children with neurodevelopmental differences. The primary objective is to highlight the importance of cultural competence and humility among professionals, researchers, and organizations in designing support groups tailored to the specific needs of Hispanic caregivers.

Significance and Impacts: In the short term, implementing culturally adapted parent training programs can lead to immediate improvements in parental stress levels and caregiver confidence within the Spanish-speaking community. Targeted support may result in improved well-being and better navigation of challenges associated with raising neurodivergent children, fostering a sense of community among caregivers. Additionally, these interventions may influence broader systems and policies in healthcare and education, promoting more culturally sensitive and inclusive services. In the long term, addressing parental stress and bolstering caregiver confidence can contribute to improved outcomes for neurodivergent children, facilitated by empowered caregivers. This project has the potential to serve as a model for supporting diverse populations and developing inclusive parent support services across various settings.

Chapter 1: Literature Review

Challenges Faced by Caregivers of Neurodivergent Children

The prevalence of neurodevelopmental disabilities manifests as developmental differences impacting social functioning and causing delays in reaching expected milestones. These disabilities encompass a wide range, including intellectual disabilities (e.g., Down syndrome), communication disorders affecting language and speech, autism spectrum disorder (ASD) affecting social communication and interaction, attention-deficit hyperactivity disorder (ADHD) affecting attention and impulsivity, and learning disabilities affecting perception and information processing (Garica et al., 2019).

Caregivers of children with neurodevelopmental disabilities often face significant stressors, and those from culturally diverse backgrounds may encounter additional stressors linked to their cultural beliefs and traditions. These challenges include communication barriers, a lack of understanding of neurodivergency, attitudes toward disability, and limited access to culturally appropriate resources (Baunmann et al., 2015). Additionally, due to the demands of caregiving for a child with neurodevelopmental disabilities, stress is a significant challenge where parents of children with ASD consistently experience higher levels of parenting stress and challenges than parents of typically developing children (Martinez & Tuner, 2022).

While stress experienced by caregivers of children with ASD has been extensively studied, there remains a necessity for a further and deeper understanding of the impact of social support on parenting stress within the cultural context of Hispanic families (Martinez & Tuner, 2022).

Many interventions are primarily designed for non-Latino White children and families, often overlooking the unique needs of culturally and socioeconomically diverse families (Magaña et al., 2020). This oversight leads to missed opportunities for interventions to effectively cater to the diverse needs of these families. A pilot study aimed at developing a parent education intervention for Latino parents of children with ASD emphasized the need to address the specific needs of Latino families rather than translating an existing intervention into Spanish (Magaña et al., 2020). In doing so, it is crucial to recognize and acknowledge the strengths within these families to create more inclusive and effective interventions. As a result, a gap exists in services that can provide much-needed support to these diverse caregivers.

Importance of Culturally Appropriate Support

Parent support group curriculums are typically designed to cater to a broad audience. However, it is crucial to acknowledge that the United States has a significant percentage of Hispanic families who are increasingly facing the challenges of raising children with neurodevelopmental disabilities but may not receive appropriate support. Nevertheless, by adopting a culturally relevant approach, support groups can create a safe and inclusive space for caregivers to connect and share experiences, which ultimately leads to better engagement and outcomes (Schilling et al., 2021). A systematic review of cultural adaptations of social skills interventions among individuals with ASD found only five studies reported on a cultural adaptation (Davenport et al., 2018). As a result, there is a need for further research to focus on parents and families from diverse cultural backgrounds, particularly those with children with disabilities. The Hispanic culture, in particular, is characterized by distinct values, customs, traditions, and beliefs that influence the caregiver-child relationship when dealing with neurodevelopmental differences. A meta-analysis of culturally adapted mental health interventions found that interventions conducted in the client's native language were twice as effective as those conducted in English, and interventions tailored for specific groups were four times more effective than those provided to all groups (Griner & Smith, 2006). Therefore, it is essential to tailor support group curriculums more effectively to cater to this population and align with their cultural context. Spanish-speaking parents deserve the opportunity to participate in parent support groups, especially when the content is relatable to their cultural background

A significant proportion of children in the United States belong to the Hispanic or non-White communities and come from households where a language other than English is spoken (Schilling et al., 2021). Consequently, there is a need for caregiver training groups that accommodate to the unique needs of Spanish-speaking populations. To effectively target this specific demographic, considerations must be made for cultural factors such as language, customs, beliefs, and values (Baunmann et al., 2015). However, the existing research on evidence-based parent training with a rigorous cultural adaptation process is limited, with only a few studies exploring the effectiveness of implementation strategies using rigorous research designs (Baunmann et al., 2015). Therefore, further investigation is necessary to better understand cultural adaptation and implementation in parent training services and practices. Additionally, there is a noticeable lack of Spanish parent support groups, and very few intervention approaches cater to the needs of Latino children with autism spectrum disorder (ASD) and other neurodevelopmental challenges (Magana et al., 2019).

Effectiveness of Support Groups

A research team investigated parents' perspectives on the effectiveness of parent-led support groups aimed at enhancing their ability to manage their children's disabilities (Law et al., 2002). This study comprised four sessions, during which twenty parents were interviewed to assess the advantages and drawbacks of their participation (Law et al., 2002). The findings indicated that parents perceived enhanced essential skills, empowerment, and a sense of community following their involvement in the sessions. Moreover, the study revealed that parents involved in support groups may experience increased emotional support by connecting with others facing similar challenges (Law et al., 2002). The heightened sense of empowerment and community could potentially lead to a reduction in overall stress and an improvement in mental well-being (Law et al., 2002).

Parent training groups can serve as a valuable resource for parents, providing them with guidance and support when needed. Unfortunately, these groups often cater primarily to the typical American family, resulting in the oversight of diverse populations, particularly the Hispanic community, which can benefit from culturally relevant parent training support. To address this issue, this study aims to examine the effectiveness of parent training support groups tailored to the cultural context of the participants. By improving the availability and accessibility of such culturally relevant parent support groups, Spanish-speaking families can gain the benefits. Cultural adaptation is defined as “the systematic modification of an evidence-based treatment (EBT) or intervention protocol to consider language, culture, and context in such a way that is compatible with the client's cultural patterns, meaning, and values” (Bernal et al., 2009). The implementation of a parent training group sensitive to their cultural background would expose parents to appropriate coaching, relevant resources, and reduce stress, ultimately enhancing their competence in navigating the challenges of raising a child with neurodevelopmental challenges. The adaptation of existing treatments and interventions could better serve the needs of children with Neurodivergent children and their families.

Advocating for Inclusive Care

While there are various forms of support groups available, and although parent-led groups can be effective, an occupational therapist can also offer additional insights and expertise to parents. The AOTA Occupational Therapy Practice Framework prioritizes client-centered care, providing occupational therapists with a foundation for leading and facilitating group sessions. Moreover, this framework encourages therapists to work closely with parents to understand their unique goals and needs, enabling them to address challenges in daily routines, provide effective strategies, and promote positive outcomes for the family as a whole (AOTA, 2020). Occupational therapy can offer assistance to children facing neurodevelopmental disabilities as well as their families. However, it is crucial to acknowledge that parents also gain significant advantages from the services of an occupational therapist.

Despite some evidence suggesting that occupational therapists can positively impact individual child goals, parental stress, and sense of competence through parent-focused coaching interventions (Allen et al., 2021), more research is needed to determine the efficacy of these approaches within a Spanish-speaking population. Peer support is also identified as a potentially valuable resource for parents of neurodivergent children, as it may improve parents' quality of life while providing proper care for their children's needs (Wong et al., 2022). Given the positive outcomes reported in the current literature regarding parent support groups, it would be beneficial to investigate the efficacy of these programs specifically for the targeted population. In light of the lack of culturally relevant resources, many Spanish-speaking families face challenges in accessing the necessary assistance. A culturally appropriate parent training group will not only be limited to pediatric settings; it could be implemented in various other settings such as hospitals, community centers, nonprofit organizations, and schools to reach a broader audience and better support these families and children. Another factor worth considering is the potential prolongation of a child's therapy session due to delays in insurance approval or therapist availability, leading to being placed on a waitlist. However, offering support to parents right from the beginning, while their child awaits services, presents an opportunity for parents to assist both themselves and their child.

Culturally Adapted Parent Support Group

In response to the above-mentioned challenges, this culturally adapted intervention will be facilitated by a Spanish-fluent occupational therapist with experience in working with children with neurodevelopmental challenges. The curriculum will cover various relevant topics, including motor development, sensory processing, emotional regulation, praxis, advocacy, and other essential aspects to help parents gain knowledge and provide more effective support for their child's development and overall well-being. The parent training group will be conducted in a virtual, group setting to provide a safe and supportive space for parents to connect with others facing similar challenges and experiences. This program is specifically tailored to support other Spanish-speaking caregivers who are also raising children with similar challenges. Through this intervention, caregivers can gain valuable insights into developmental foundations, acquire a deeper understanding of individual differences, and receive support for reflective parenting. By drawing from the experiences and cultural background of Spanish-speaking caregivers, the intervention ensures that it resonates with the specific needs and values of the target caregivers it serves. Providing this level of support can have a positive impact on the quality of care that these parents offer to their children with neurodevelopmental challenges (Meadan, 2020). By addressing cultural barriers and offering relevant guidance, the culturally adapted intervention aims to empower and strengthen caregivers, ultimately benefiting both the caregivers and their children.

Parents of children with neurodevelopmental challenges bear the primary responsibility for caring for their children, which can lead to increased stress and reduced confidence in their parenting abilities. Occupational therapists and other professionals from different disciplines should take these parents' wants and needs into consideration to ensure the success of their child's development and enhance their personal well-being.

Chapter 2: Needs Assessment

The initial needs assessment interview took place with occupational therapist, Joann Fleckenstein at ITTS (Individual and Team Services) Family for Children. This interview was approved by the Institutional Review Board (IRB) at the Georgia State University (GSU). Fleckenstein has been actively engaged in the development and presentation of parent support and training groups since 2021. Her focus has predominantly centered on English speakers in Atlanta, GA, complemented by the establishment of a specialized Spanish Speaker's Parent Support Group within the clinic. Additionally, she has extended her efforts to present parent support sessions to individuals in Latin America, utilizing a curriculum tailored for Spanish speakers. Recognizing the paramount importance of culturally tailored parent training, Fleckenstein emphasizes the necessity to align content with the cultural backgrounds of the parents. She acknowledges the challenges inherent in meeting the individual needs within diverse cultural groups and emphasizes the effectiveness of targeting more homogeneous groups for specific support.

In terms of feedback from Spanish-speaking caregivers, Fleckenstein reports significant difficulties faced by this demographic in accessing parental support groups. Identified obstacles include social stigma, a lack of Spanish-language resources, and practical issues such as financial constraints and transportation difficulties. When discussing the tailoring of curriculum to address cultural needs, Fleckenstein highlights the importance of various approaches to support the unique cultural requirements of Spanish-speaking caregivers. She highlights the necessity of considering cultural norms, dialects, religious/faith backgrounds, and regional differences when developing a support group curriculum. Fleckenstein further points out the key benefits of culturally appropriate support groups, noting that caregivers significantly benefit from culturally aligned support as it provides essential context to their experiences. She illustrates the impact of cultural misunderstandings in healthcare settings and emphasizes the need for cultural sensitivity to prevent alienation between caregivers and providers.

Regarding the integration of capstone project findings, Fleckenstein suggests that the insights gained from the project can be effectively incorporated into existing interventions or programs supporting caregivers and children with neurodevelopmental challenges. She particularly emphasizes the potential for improving caregiver outcomes through the implementation of culturally relevant support. In conclusion, Joann Fleckenstein's extensive experience and insights highlight the critical need for culturally relevant parent support training, especially for Spanish-speaking caregivers of neurodivergent children facing unique challenges.

Chapter 3: Methods

Participants

The study involved three caregivers/parents of neurodivergent children who participated in the research. The IRB at GSU approved the study. All participants read and signed an informed consent form.

Recruitment

Participants were recruited from local outpatient occupational therapy clinics. Therapists assisted in the recruitment process by referring potential participants using study flyers. Recruitment flyers were emailed to caregivers and parents through Facebook groups, parent groups, and therapy practices.

Inclusion/Exclusion Criteria

Inclusion criteria for participation in the study included being a Spanish-speaking parents/caregivers and having a child with neurodevelopmental disabilities, being able to participate in at least 50% of the sessions. The exclusion criteria included parents/caregivers to a child not receiving therapeutic services.

Proposed Intervention

The intervention consisted of a two-day virtual workshop conducted over a two-week period. Each week included one session, with each session lasting four hours. The workshop focused on providing neurodivergent affirming care, addressing the specific needs and challenges faced by families with neurodivergent children. This curriculum covered essential topics related child development, parenting challenges, advocacy, and emotional well-being.

The workshop was facilitated by a Spanish-fluent occupational therapist with experience in working with children with neurodevelopmental differences. Additionally, she is a mother of children with neurodevelopmental differences. Questions related to the content of the program were sent via a Qualtrics link between sessions. Lastly, participants completed the Parental Stress Scale Questionnaire at the beginning and end of the intervention to assess changes in stress levels.

Site Description

The study took place at a local Atlanta outpatient occupational therapy clinic, Individual and Team Therapy Services (ITTS) for Children. Established in 1986 by Dr. Milagros Cordero and Mr. Barry Landry, ITTS for Children has been at the forefront of providing client-centered and family-focused care. Dr. Cordero actively participated in the development of the DIRFloortime Model, meeting with Dr. Stanley Greenspan and Dr. Serena Weider during the early development of the model. As such, the clinic is firmly rooted in this developmental approach. The therapists at this clinic offer services across all ages for individuals of all neurotypes and their families. ITTS for Children uses the DIRFloortime model of intervention, which is a strengths-based and developmental approach that takes into consideration the individual differences of each client and their family members. This includes providing culturally relevant support. Additionally, this clinic offers parent support and coaching on neurodiversity and advocacy for their child. Based on these factors, this site aligned with the goals of this project to address the needs of Spanish-speaking caregivers with children with neurodivergent disabilities. Although the training was conducted online, the site was used by the occupational therapist leading the sessions.

Assessments

The primary assessment used in the study was a Spanish-translated version of the Parental Stress Scale (PSS) Questionnaire. The PSS is a self-report questionnaire aimed to measure parental stress levels and evaluate the impact of the intervention on reducing stress among participants (Berry & Jones, 1995). This tool was administered at two-time points: at the beginning and end of the intervention period. Moreover, the PSS effectively evaluates parental stress across various domains, including anxiety, loneliness, marital satisfaction, and social support (Zelman & Ferro, 2018). Participants also completed a survey via Qualtrics following the first session. This survey aimed to gather information about caregivers' experiences with implementing strategies discussed during the first session for their child's behavior and well-being. The survey addressed the use of strategies, challenges encountered, positive outcomes observed, changes in the child's behavior or well-being, and any difficulties faced in parenting while implementing the strategies.

Statistical Analysis

A quasi-experimental design with pre- and post-assessments was used for the statistical analysis. Data analysis was conducted using IBM SPSS Statistics (Version 29). The primary analysis involved comparing parental stress scores before and after the intervention to determine the effectiveness of the parent training program. It was anticipated that participation in the workshop would lead to a decrease in parental stress levels, indicating the success of the intervention in providing support and guidance to Spanish-speaking families with neurodivergent children. To compare data of the parental parent stress scores collected during the study, the Wilcoxon signed-rank test was utilized to determine a statistical difference between the pre-and post-parental stress scores. This test was chosen due to the small sample size. In addition, participant discussions during the training sessions were summarized.

Chapter 4: Results

Parental Stress Scale

The study aimed to assess the effectiveness of a parent group training program in reducing parental stress among Spanish-speaking caregivers with neurodivergent children. The PSS utilized in this study provides a potential total score ranging from 18 to 90, with lower scores indicating lower levels of perceived parental stress and higher scores indicating greater stress. Participants' self-reported parental stress levels were assessed before and after the parent group training program. Descriptive statistics revealed a decrease in parental stress scores from pre-training (*Mean* = 36, *SD* = 9.64) to post-training (*Mean* = 25.67, *SD* = 2.31). The p-value of the Wilcoxon signed-rank test was found to be (p = .109). As the hypothesis was one-tailed, anticipating post-test scores to be lower, the p-value was divided by 2, resulting in a one-tailed p-value of .0545. This value lies on the borderline of statistical significance. Therefore, with a larger sample size, it is likely that a significantly lower score would be observed in the post-test. Thus, the parent training sessions would have a potential effect on parental stress scores.

Caregiver Survey

The participants' responses indicated a consistent practice of allowing their child to choose activities and dedicating individual time to each child. They emphasized bonding, engagement, and shared play as integral components of their interactions. Despite occasional time constraints, participants viewed implementing strategies as a checklist, ensuring they allocated time for important priorities before the day ended. They acknowledged that utilizing these strategies required patience and time investment. In managing conflicts, they described situations where they effectively intervened to address their child's emotions and facilitate resolution, resulting in peaceful play. They also employed strategies such as joining their child's preferred play, engaging in parallel play, and gradually transitioning to shared moments, contributing to a calmer atmosphere. Participants reported enjoyment in shared activities and noted unexpected improvements in their children's behavior without the need for disciplinary measures, such as raising their voices. Overall, participants did not encounter any significant difficulties with parenting while implementing these strategies during the week.

Caregivers’ Experiences

Five major themes were identified regarding caregivers’ experiences and perceptions of raising a child with neurodivergent differences that participants shared during the session. First and foremost, the Emotional Impact and Coping strategies used in the face of adversity were highlighted, thus emphasizing the resilience and strength of their roles. Furthermore, Cultural Factors and Beliefs added depth to their caregiving experiences, influencing their perceptions and approaches due to language barriers and cultural attitudes. Adaptation and Flexibility emerged as essential qualities, as caregivers continuously adjusted their approaches to meet the unique needs of their children. Social Dynamics and Relationships played a pivotal role, shaping both the support networks they relied on and the interactions within their communities. Lastly, Support Strategies utilized revealed an abundance of resilience and innovation as caregivers shared their methods for navigating the complexities of raising neurodivergent children. This reflective journey uncovered the challenges as well as the profound strength and unity that defined the experiences of Spanish-speaking caregivers in this community.

Emotional Impact and Coping

Participants described experiencing a range of emotional challenges. Some caregivers initially resisted or denied their child's neurodivergent diagnosis, struggling with feelings of shock, disbelief, doubt, or fear about what it meant for their child's future. The unpredictable nature of neurodivergence created feelings of uncertainty about the best course of action for their child. This uncertainty often led to stress and anxiety about making the right decisions for their child. Caregivers expressed experiencing anxiety when finding and accessing appropriate resources and support. The daily challenges of caregiving led to emotional distress, including feelings of overwhelm, sadness, or helplessness, as caregivers navigated the needs of their child while managing other responsibilities. Caregivers reported struggling with feelings of guilt or self-blame, questioning their parenting decisions or wondering if they could have done something differently to prevent or alleviate their child's neurodivergence. Coping with their child’s differences led to frustration and exhaustion for caregivers, making it difficult to meet their child's needs effectively. Caregiving tended to be physically, emotionally, and mentally draining, requiring constant attentiveness and energy to meet their complex needs. Caregivers experienced feelings of rejection or isolation from friends, family members, or society at large, who did not understand or accept their child's neurodivergence. Caregivers struggled with feelings of inadequacy or worthlessness, especially if they perceived themselves as failing to meet expectations or if they felt judged or criticized by others. Despite the challenges, many caregivers found a sense of empowerment in advocating for their child, learning about their child's needs, and connecting with supportive communities. Caregivers cultivated compassion not only for their child but also for themselves and others in similar situations, fostering understanding and empathy within their families and communities.

Cultural Factors and Beliefs

The participants prioritized maintaining their cultural identity by cherishing their heritage, deriving strength from their traditions, and fostering connections with others with similar backgrounds. Language was a significant barrier as caregivers navigated to access information on their child’s condition, treatment options, and support services, as many resources were primarily English and not in their native language of Spanish. Additionally, language could also serve as a bridge, fostering connections within Spanish-speaking communities and facilitating cultural understanding and advocacy efforts. Within their communities, caregiving was a collaborative effort, with extended family members actively participating in the child's upbringing, reflecting the importance of the family unit in their culture. Also, these caregivers often turned to spirituality and religious beliefs for solace and guidance, leaning on faith-based practices such as prayer during challenging times to find comfort and strength. Despite the richness of their cultural heritage, caregivers faced hurdles ranging from varying attitudes toward neurodivergence to dealing with stigma and societal norms that influenced their acceptance and integration within their communities. Furthermore, cultural customs shaped how caregivers communicated emotions and needs, impacting their interactions with healthcare providers and support networks. Caregivers described experiencing a lack of cultural humility by healthcare providers and support, where there was not an adequate acknowledgment and awareness of cultural differences. To navigate these difficulties, Spanish-speaking caregivers saw the value of seeking assistance from culturally sensitive organizations and groups, reaching into community support networks to access resources and establish connections that aided them in their journey of raising a neurodivergent child.

Adaptation and Flexibility

Participants demonstrated flexibility by adjusting their caregiving approach to accommodate their child's unique needs and changing circumstances. They embraced change as they navigated the dynamic nature of neurodivergence and its impact on their child's development. For most, it was essential for caregivers to modify their parenting style to emphasize patience, consistency, and support tailored to their child's needs. Additionally, they relied on intuition and instincts to understand their child's needs and make informed decisions about their care and treatment.

Social Dynamics and Relationships

Participants cultivated empathy for their children and for others either diagnosed with neurodevelopmental disabilities and their caregivers, fostering connections and understanding within their families and communities. This empathy drove caregivers to exhibit compassion, motivating them to support and advocate for their child while also educating others about autism and promoting acceptance and inclusion. However, caregivers experienced feelings of disrespect or misunderstanding from those who lacked awareness or sensitivity to their child's differences, resulting in frustration and isolation. Additionally, some caregivers encountered naivety or ignorance about neurodivergence within their social circles, requiring patience and education to challenge misconceptions and promote greater understanding and acceptance.

Support Strategies

Participants often found empowerment in advocating for their child's needs and accessing support from understanding communities. Despite facing significant challenges, they became pillars of support and guidance for other families, generously offering insights, resources, and wisdom to empower and uplift others navigating similar experiences. Through sharing their stories and knowledge, they created a network of understanding and unity, fostering a sense of community among families affected by similar circumstances. Feeling seen and appreciated for their efforts provided validation and encouragement, helping caregivers maintain their resilience and continue providing the best possible care for their child.

Chapter 5: Discussion and Impact

This study sought to determine the efficacy of a culturally adapted parent training group curriculum in providing guidance and support to Spanish-speaking families with neurodivergent children. In the study, three caregivers completed the PSS questionnaire both before and after participating in a parent group training workshop. The analysis revealed a decrease in reported stress levels from the pre-workshop assessment to the post-workshop assessment among all three participants. However, despite the lack of statistical significance, the anticipated outcome of reducing parental stress was evident, which indicates that the program may have had a beneficial impact on participants' stress levels and the potential to make a difference in the lives of caregivers with children with neurodivergent differences. This suggests that while the workshop may have had a positive impact on participants' perceived stress levels, the change was not substantial enough to reach statistical significance within the small sample size of three caregivers. Although the findings did not achieve statistical significance, they still provide valuable insights into the potential benefits of parent group training workshops in addressing parental stress and bolstering caregiver confidence.

Overall, the study highlighted the rich and complex experiences of Spanish-speaking caregivers raising neurodivergent children, as shared through parent group sessions. Five major themes - Emotional Impact and Coping, Cultural Factors and Beliefs, Adaptation and Flexibility, Social Dynamics and Relationships, and Support Strategies - emphasized the resilience within this community. These insights not only shed light on the challenges faced but also revealed the strength in their caregiving journeys. These caregivers navigated a range of emotions, from shock and disbelief to anxiety and guilt, as they confronted the uncertainties and challenges inherent in caregiving. Despite facing rejection and isolation from society, caregivers found empowerment in advocating for their children and connecting with supportive communities. Cultural factors further shaped their experiences, with caregivers drawing strength from their heritage while grappling with stigma and societal norms. Adaptation and flexibility emerged as essential qualities as caregivers adjusted their approaches to meet their child's evolving needs. Within their social dynamics, caregivers cultivated empathy and compassion, advocating for acceptance and understanding while challenging misconceptions. Through sharing their stories and coping strategies, Spanish-speaking caregivers created a network of support and unity, offering guidance and validation to others navigating similar experiences. This reflective journey not only highlighted the challenges but also emphasized the profound strength that defined the experiences of Spanish-speaking caregivers in raising neurodivergent children.

The results and output of this study are crucial in the context of the research question and its relevance to occupational therapy (OT). First, the study highlights the effectiveness of a culturally adapted parent training group curriculum in supporting Spanish-speaking families with neurodivergent children. Despite the lack of statistical significance in the reduction of reported stress levels among participants, the observed decrease still provides valuable insights into the potential benefits of such interventions. This fills a gap in the literature by addressing the specific needs of this particular population within the neurodiversity community, thus contributing to a more inclusive approach to OT practice. Additionally, it acknowledges and respects the unique cultural contexts and challenges faced by these families, thus advocating for interventions that are not only effective but also culturally sensitive and relevant. Such an approach aligns with the fundamental principles of occupational therapy, which emphasize the importance of holistic care tailored to individual needs (AOTA, 2020). Ultimately, by bridging the gap between research findings and real-world application, this study contributes to enhancing the quality of care and support available to Spanish-speaking families with neurodivergent children within the occupational therapy framework.

In the short term, solving the gap of this research question through the implementation of culturally adapted parent training programs can lead to improvements in parental stress levels and caregiver confidence within the Spanish-speaking community. By providing targeted support and guidance, families may experience improved well-being and to better navigate the challenges associated with raising neurodivergent children. Additionally, the creation of such programs can foster a sense of community among caregivers, offering a platform for mutual support and sharing of experiences. Furthermore, the impacts of these interventions may extend beyond individual families to influence broader systems and policies within the healthcare and education sectors. Increased awareness of the unique needs of Spanish-speaking caregivers and their children may prompt the development of more culturally sensitive and inclusive services. This can lead to improved access to resources and support for underserved communities, ultimately reducing disparities in healthcare and educational outcomes.

In the long term, the potential impacts of addressing parental stress and bolstering caregiver confidence through culturally adapted interventions are profound. By equipping families with the necessary skills and support networks, these programs can contribute to improved long-term outcomes for neurodivergent children, provided by the effects of empowered caregivers. The impact and significance of this project lie in its potential to empower Spanish-speaking families to better support their neurodivergent children. By providing culturally adapted parent training support, we aim to reduce stress, increase parental competence, and enhance the overall well-being of both parents and children. This project has the potential to serve as a model for addressing the needs of diverse populations facing similar challenges and contribute to the development of more inclusive and culturally sensitive parent support services in various settings.

Limitations

Several limitations were noted throughout the study, the most prominent being its small sample size. Although there was a lack of statistical significance, it is noteworthy to consider that the findings are approaching significance even with a limited sample size of three participants. Further research with larger sample sizes and possibly the inclusion of a control group may permit further research to thoroughly evaluate the effectiveness of such interventions. Another limitation is the generalizability of the findings, as the results may not accurately represent the broader population of Spanish-speaking caregivers. More so, while caregivers shed light on caregiver experiences and the unique impact of Hispanic culture on their challenges, this should prompt further investigation or considerations when engaging with this specific demographic. Furthermore, it's critical to recognize that Hispanics represent a varied range of ethnic backgrounds. In doing so, interventions should take this diversity into account and may call for modifications according to the particular cultural context of the region in which they are implemented (Magaña et al., 2017). Additionally, the short duration of the study may have limited the ability to detect more significant changes in stress levels. This brief period might have also hindered caregivers' ability to implement strategies discussed in the curriculum into their daily routines with their children, potentially affecting stress levels. Lastly, the study did not account for specific variables such as the type of neurodevelopmental disability, the child's age, or other family demographics in its analysis.

While several themes regarding caregivers’ shared experiences and perceptions of raising a child with neurodevelopmental disabilities emerged from participants during this study, utilizing more robust qualitative measures could have significantly enhanced the quality and accuracy of the results and perspectives obtained. While capturing these shared experiences and perceptions was valuable for capturing subjective experiences and insights, it has inherent limitations because it relies on individual recollections and perceptions that may be biased or inconsistent. Utilizing more rigorous qualitative methods, such as in-depth interviews, focus groups, or structured observations, would have allowed for a deeper exploration of participants' experiences, attitudes, and behaviors related to parental stress and caregiving of their neurodivergent child before and after the workshop. These measures might provide richer data, allowing researchers to uncover underlying key patterns and themes in participants' narratives with greater precision and reliability. By utilizing more robust qualitative measures, future research can better capture the nature of parental stress and the potential impacts of culturally tailored intervention programs, thereby establishing more accurate insights for improving support services and interventions for Spanish-speaking caregivers.

Sustainability Plan

Engagement/Measurable Goals:

The program aims to increase caregiver participation annually, reduce the level of caregiver stress, and enhance caregiver satisfaction. The program will conduct the support group three times a year, providing opportunities for participation in the Spring, Summer, and Fall seasons. The program will be offered to the Hispanic community in the local metro Atlanta area by the end of 2024.

OT Engagement/Training:

The success of the program centers on the recruitment and training of qualified OT facilitators, preferably Spanish speakers. The current program caters to children of families receiving or previously experiencing the DIRFloortime model. The facilitators will be required to have a background in understanding neurodiversity and be DIRFloortime experts as the program utilizes common language and ideas rooted in DIRFloortime. However, because of the growth in understanding among clinicians about offering neurodiversity affirming care the information shared is likely to be considered common knowledge versus terms specific to DIRFloortime. To ensure further sustainability of the program in the future, the goal is to adapt the program for Spanish-speaking families that have not experienced the DIR floortime approach. The training will be modified to provide more broad-based information on development versus using DIRFloortime-specific language. This will allow more OT facilitators, which are not DIR Floortime experts, to facilitate the program, thus reaching a larger target audience.

Community Support:

Building strong community support, specifically with the Hispanic community, is essential for the program's continuity. The initiative involves identifying and cultivating relationships with stakeholders, community leaders, and organizations that can advocate for and support the continuation of the support groups. Marketing and outreach campaigns will be implemented to raise awareness, and positive testimonials from caregivers will be used to showcase the program's impact.

Integration with Services:

The program aims to integrate itself with existing neurodevelopmental clinics, centers, occupational therapy (OT) settings, pediatric clinics, and other relevant facilities. By leveraging their infrastructure and resources, the program can become an integral part of the broader support network. Collaborating with therapists, healthcare providers, and educators will help incorporate the support group into their practices, reinforcing its importance.

Data Collection/Evaluation:

The sustainability of the program relies on continuous data collection and evaluation. It aims to demonstrate the positive impact of the intervention by reducing caregiver stress, increasing their confidence, and enhancing overall well-being. This data will be crucial in attracting further funding and support for the program. To achieve this, client satisfaction surveys will be conducted regularly, and facilitators will gather feedback to ensure program effectiveness.

Cultural Relevance/Adaptability:

Cultural relevance is a critical aspect of the program's sustainability. It guarantees that the support group remains culturally appropriate and responsive to the unique needs of the caregiver population. Regular assessments and updates will be made to address any cultural changes or evolving community needs, ensuring that the intervention remains effective and inclusive.

Conclusion

In conclusion, this study sheds light on the efficacy of a culturally adapted parent training group curriculum in supporting Spanish-speaking families raising neurodivergent children. While the analysis revealed a decrease in reported stress levels among participants following the parent group training workshop, the observed reduction did not reach statistical significance within the small sample size of three caregivers. Nonetheless, these findings provide valuable insights into the potential benefits of parent group training workshops in addressing parental stress and bolstering caregiver confidence. The experiences and perceptions of Spanish-speaking caregivers uncovered through this research underscore the resilience and solidarity within this community as they navigate the complexities of caregiving. By acknowledging cultural factors and fostering adaptation and flexibility, caregivers empower themselves and their children while advocating for acceptance and understanding. This project's impact lies in its potential to empower Spanish-speaking families, reduce stress, and enhance overall well-being. Moving forward, these findings can inform the development of more inclusive and culturally sensitive parent support services, ultimately improving outcomes for neurodivergent children and their families across diverse populations.

References

Allen, S., Knott, F. J., Branson, A., & Lane, S. J. (2021). Coaching Parents of Children with Sensory Integration Difficulties: A Scoping Review. Occupational Therapy International, 1–11.

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). American Journal of Occupational Therapy, 74(Suppl. 2), 7412410010.

Baumann, A. A., Powell, B. J., Kohl, P. L., Tabak, R. G., Penalba, V., Proctor, E. E., Domenech-Rodriguez, M. M., & Cabassa, L. J. (2015). Cultural Adaptation and Implementation of Evidence-Based Parent-Training: A Systematic Review and Critique of Guiding Evidence. Children and youth services review, 53, 113–120.

Bernal, G., Bonilla, J., & Bellido, C. (1995). Ecological validity and cultural sensitivity for outcome research: Issues for the cultural adaptation and development of psychosocial treatments with Hispanics. Journal of abnormal child psychology, 23(1), 67-82.

Berry, J. O., & Jones, W. H. (1995). The parental stress scale: Initial psychometric evidence. Journal of Social and Personal Relationships,12, 463–472.

Davenport, M., Mazurek, M., Brown, A., & McCollom, E. (2018). A systematic review of cultural considerations and adaptation of social skills interventions for individuals with autism spectrum disorder. Research in Autism Spectrum Disorders, 52, 23–33.

Garcia, S., Hall-Lande, J., & Nye-Lengerman, K. (2019). Factors influencing low prevalence of neurodevelopmental disabilities among US Hispanic/Latino children. *J Racial Ethn Health Disparities*, *6*(6), 1107–1121

Law, M., King, S., Stewart, D., & King, G. (2001). The perceived effects of parent-led support groups for parents of children with disabilities. Physical & Occupational Therapy in Pediatrics, 21(2–3), 29–48.

Martinez, V. C., & Turnage, D. (2022). Social Support and Parenting Stress in Hispanic Parents of Children with Autism Spectrum Disorder. *Issues in Mental Health Nursing, 43*(11), 1030–1040.

Magaña, S., Lopez, K., Salkas, K., Iland, E., Morales, M. A., Garcia Torres, M., Zeng, W., & Machalicek, W. (2020). A Randomized Waitlist-Control Group Study of a Culturally Tailored Parent Education Intervention for Latino Parents of Children with ASD. Journal of autism and developmental disorders, 50(1), 250–262.

Meadan, H., Adams, N. B., Hacker, R. E., Ramos-Torres, S., & Fanta, A. (2020). Supporting Spanish-speaking families with children with disabilities: Evaluating a training and coaching program. Journal of Developmental and Physical Disabilities, 32(3), 489–507.

Schilling, S., Mebane, A., & Perreira, K. M. (2021). Cultural Adaptation of Group Parenting Programs: Review of the Literature and Recommendations for Best Practices. Family process, 60(4), 1134–1151.

Wong, T. S. M., & Shorey, S. (2022). Experiences of peer support amongst parents of children with neurodevelopmental disorders: A qualitative systematic review. Journal of pediatric nursing, 67, e92–e99.

Zelman, J. J., & Ferro, M. A. (2018). The Parental Stress Scale: Psychometric Properties in Families of Children With Chronic Health Conditions. Family Relations, 67(2), 240–252.

Appendix 1: Learning Objectives

1. The student will develop an understanding on the efficacy of a parent training group through program curriculum and evaluation.
2. The student will demonstrate understanding of the needs of Hispanic caregivers of children with neurodivergencies within appropriate cultural context.
3. Student will gain understanding of additional strategies that will be supportive for parents to utilize for better understanding of their child and neurodevelopmental challenges.

Appendix 2: Supervision Plan

Capstone Student Roles and Responsibilities:

1. Adhere to Georgia State University program policies and procedures relevant to the capstone.
2. Complete the 14-week (560-hour) capstone experience, ensuring that no more than 20% of the time is spent outside the mentored practice setting. If any hours are missed, arrange appropriate makeup hours in consultation with the site mentor and capstone coordinator.
3. Prior to commencing the capstone experience, the student must fulfill the requirement of completing and submitting the Institutional Review Board (IRB) application.
4. Collaborate to develop the MOU with the site mentor and the Capstone Coordinator including Individualized Specific objectives, and plan for supervision
5. Carry out assigned tasks from the site mentor to ensure a successful learning experience, alignment with chosen focus areas, and achievement of desired capstone outcomes.
6. Proactively maintain communication with the site mentor, occupational therapy faculty, and doctoral capstone coordinator as necessary to ensure a successful capstone experience.
7. Engage in respectful and effective interaction and communication with the site mentor, faculty mentor, and doctoral capstone coordinator
8. Embrace and apply feedback received from the site mentor, faculty mentor, and capstone coordinator to facilitate personal and professional growth.
9. Demonstrate professionalism throughout the capstone, including proficient time management, meeting deadlines, and maintaining regular communication with the capstone team.

10. Accurately, and in an organized manner, collect, manage, and analyze data for the capstone project.
11. Exhibit self-directedness during the entire capstone process, encompassing the development, planning, and successful completion of the capstone experience and project.
12. Take the initiative to complete all necessary documentation with the site mentor, faculty mentor, or capstone coordinator.
13. Provide constructive feedback to the site during the midterm and final evaluations.
14. Conclude the capstone experience by disseminating the culminating capstone project within the prescribed time frame set by the academic program.

Site Mentor Roles and Responsibilities:

1. Orient the student to the capstone site, including policies, procedures, expectations, personnel, and stakeholders.
2. Assist the student in carrying out specific learning activities aligned with their learning objectives.
3. Provide supervision and feedback throughout the capstone experience as defined by the MOU
4. Assist the student in applying knowledge to practical situations, and develop problem-solving skills and practical competencies.
5. Collaborate with the student to establish clear mentorship responsibilities.
6. Provide continuous supervision and mentorship throughout the capstone experience.
7. Offer insightful and constructive feedback on the student's performance during the capstone experience.

8. Work with the student to maintain a system for documenting the student's hours on-site and tracking tasks and activities accomplished during that time.
9. Provide guidance on the practical aspects of completing work-related requirements at the capstone site, such as workflow, hours of operation, and workspace access.
10. Proactively communicate with the capstone team to address any potential concerns.
11. Maintain regular communication with the student and capstone team, either in person, virtually, via phone, or email, to provide feedback on progress, implementation and documentation.
12. Offer meaningful and timely feedback on drafts of the capstone project as needed.
13. Provide evaluations of the student's performance and progress toward achieving learning objectives through a midterm and final evaluation.

Project Requirements:

The student must fulfill a 14-week capstone experience, with no more than 20% of the time spent outside the mentored practice setting, totaling 560 hours. To track the completion of required hours, the student will maintain a time log. At the end of each week, both the student and site mentor will initial the log, and the total hours completed will be documented and signed off by the mentor and the student at the completion of the capstone experience. In addition to the hours, the student is expected to produce deliverable materials as part of the capstone experience. A timeline for submitting deliverables will be developed by the student.

Communication Methods:

The student and the site mentor are encouraged to maintain open communication through various channels, including in-person meetings, email, phone calls, text messages, and WebEx meetings.

It is expected that the student will initiate and sustain regular communication with the site mentor. The student and site mentor are expected to respond within one business day.

Scheduled Meetings:

The site mentor and student will schedule routine weekly in-person or virtual meetings lasting approximately 30 minutes to discuss the student's progress in relation to the capstone experience. Prior to each meeting, the student will submit any scheduled deliverables to the site mentor for review. Additionally, the student will maintain a log documenting the details of each meeting, including the topics discussed and any deliverables submitted. After each meeting, both the student and site mentor will initial the log, and at the end of the capstone experience, both parties will sign the log. The student may also interact with and meet the site mentor throughout the week as needed and as scheduling permits.

Collegiality/Resolving Disputes:

During the capstone experience, the student and site mentor will maintain an open and collaborative relationship to work towards achieving the goals and outcomes of the capstone project. Respectful and professional interactions are expected from both parties throughout the capstone experience.

If a conflict arises during the student's time at the capstone site, the student and site mentor will schedule a meeting to address and discuss the issue. Maintaining open communication, both the mentor and the student will ensure that conflicts are promptly dealt with and will collaboratively explore potential solutions. If further action is needed to resolve the matter, the student will contact the faculty mentor and doctoral capstone coordinator for assistance and guidance.

OTD Program Curricular Design:

The student's capstone project will align with GSU's OTD program curricular design, following these key ideas:

1. **Understanding and utilizing occupation to promote health and wellness.**

   The capstone project will focus on empowering caregivers with the knowledge and skills needed to support their children's development effectively. By promoting caregiver participation in this support group, the project aligns with the core principle of utilizing occupation to foster health and wellness in both caregivers and children with neurodevelopmental challenges.

2. **Use of evidence-based practice to support the doctoral capstone project.**

   This capstone project seeks to evaluate the efficacy of the parent training support group for caregivers of children with neurodevelopmental challenges. By conducting a thorough assessment of the program's outcomes, this project follows the utilization of evidence-based practice principles.

3. **Understanding and using professional ethics and values.**

   As part of the capstone project, the well-being and rights of the caregivers and their children must be protected. This involves respecting confidentiality, obtaining informed consent, and conducting the research with integrity and professionalism.

4. **Enhancing advocacy and leadership skills**

   The capstone project serves as an opportunity for the student to demonstrate their advocacy and leadership skills. By actively participating in the creation and implementation of a culturally appropriate support group, students advocate for the needs of Hispanic caregivers and their children with neurodevelopmental challenges. Also, the student will show leadership by contributing to the development of a program that promotes the well-being of caregivers.

5. **Lifelong professional growth and development.**

   Participating in this capstone project allows the students to engage in real-world, hands-on experiences that contribute to their lifelong professional growth and development. The project provides an opportunity to apply knowledge, strengthen research skills, and collaborate with professionals and caregivers.

6. **Enhancing diversity, inclusion, and cultural competence.**

   The capstone project specifically focuses on designing a culturally appropriate support group for Hispanic caregivers of children with neurodevelopmental challenges. By doing so, the project represents the commitment to diversity, inclusion, and cultural humility in the field of occupational therapy.

Appendix 3: Parental Stress Scale

The following statements describe feelings and perceptions about the parenting experience. Think about each of the items in terms of what your relationship with your child or children is normally like. Indicate the degree to which you agree or disagree with the following statements (Berry & Jones, 1995).

- 1 = Strongly disagree
- 2 = Disagree
- 3 = Undecided
- 4 = Agree
- 5 = Strongly agree

1. I am happy in my role as a parent.
2. There is little or nothing I wouldn't do my child(ren) if it was necessary.
3. Caring for my child(ren sometimes takes more time and energy than I have to give.
4. I sometimes worry whether I am doing enough for child(ren).
5. I feel close to my child(ren).
6. I enjoy spending time with my child(ren).
7. My child(ren) is an important source of affection for me.
8. Having child(ren)gives me a more certain and optimistic view for the future.
9. The major source of stress in my life is my child(ren).
10. Having child(ren) leaves little time and flexibility in my life.
11. Having child(ren) has been a financial burden.
12. Is it difficult to balance different responsibilities because of my child(ren).

13. The behavior of my child(ren) is often embarrassing or stressful to me.
14. If I had to do over again, I might decide not to have child(ren).
15. I feel overwhelmed by the responsibilities of being a parent.
16. Having child(ren) has meant having too few choices and too little control over my life.
17. I am satisfied as a parent.
18. I find my child(ren) enjoyable.

Spanish Parental Stress Scale:

Las siguientes afirmaciones describen sentimientos y percepciones sobre la experiencia de ser padre o madre. Piense en cada uno de los puntos en términos de cómo es normalmente su relación con su hijo o hijos. Indique el grado en que está de acuerdo o en desacuerdo con las siguientes afirmaciones.

- 1 = Muy en acuerdo
- 2 = En desacuerdo
- 3 = Indeciso
- 4 = En acuerdo
- 5 = Muy de acuerdo

1. Me siento feliz en mi papel como padre/madre
2. No hay nada o casi nada que no haría por mi hijo/a si fuera necesario
3. Atender a mi hijo/a a veces me quita más tiempo y energía de la que tengo
4. A veces me preocupa el hecho de si estoy haciendo lo suficiente por mi hijo/a
5. Me siento muy cercano/a a mi hijo/a
6. Disfruto pasando tiempo con mi hijo/a

7. Mi hijo/a es una fuente importante de afecto para mí
8. Tener un hijo/a me da una visión más certera y optimista para el futuro
9. La mayor fuente de estrés en mi vida es mi hijo/a
10. Tener un hijo/a deja poco tiempo y flexibilidad en mi vida
11. Tener un hijo/a ha supuesto una carga financiera
12. Me resulta difícil equilibrar diferentes responsabilidades debido a mi hijo/a
13. El comportamiento de mi hijo/a a menudo me resulta incómodo o estresante
14. Si tuviera que hacerlo de nuevo, podría decidir no tener un hijo/a
15. Me siento abrumado/a por la responsabilidad de ser padre/madre
16. Tener hijo/hijos ha significado tener demasiadas pocas opciones y demasiado poco control sobre mi vida.
17. Me siento satisfecho/a como padre/madre
18. Disfruto de mi hijo/a

Appendix 4: Institutional Review Board

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999 In Person: 3rd Floor
Atlanta, Georgia 30302-3999 58 Edgewood
Phone: 404/413-3500 FWA: 00000129

December 12, 2023

Principal Investigator: Sutanuka Bhattacharjya

Key Personnel:	Bhattacharjya, Sutanuka; Castro, Daniela S
Study Department:	Department of Occupational Therapy
Study Title:	Online Education and Support Group on Neurodivergent Affirming Care for Spanish-Speaking Caregivers
Review Type:	Expedited Category 7
IRB Number:	H24119

Approval Date: 12/10/2023

Status Check Due By: 12/09/2026

The Georgia State University Institutional Review Board (IRB) reviewed and approved the above-referenced study in accordance with 45 CFR 46.111. The IRB has reviewed and approved the study and any informed consent forms, recruitment materials, and other research materials that are marked as approved in the application. The approval period is listed above. Research that has been approved by the IRB may be subject to further appropriate review and approval or disapproval by officials of the Institution.

It is the Principal Investigator’s responsibility to ensure that the IRB’s requirements as detailed in the Institutional Review Board Policies and Procedures For Faculty, Staff, and Student

Researchers (available at gsu.edu/irb) are observed and to ensure that relevant laws and regulations of any jurisdiction where the research takes place are observed in its conduct.

Federal regulations require researchers to follow specific procedures in a timely manner. For the protection of all concerned, the IRB calls your attention to the following obligations that you have as Principal Investigator of this study.

1. For any changes to the study (except to protect the safety of participants), an AmendmentFormmust be submitted to the IRB.The AmendmentFormmust be reviewed and approved before any changes can take place.
2. Any unanticipated problems occurring as a result of participation in this study must be reported immediately to the IRB using the Unanticipated Problem Form.
3. Principal investigators are responsible for ensuring that informed consent is properly documented in accordance with 45 CFR 46.116.

   ☐ A Waiver of Documentation of Consent has been approved for this study in accordance with the requirements set forth in 45 CFR 46.117 c.
4. A Status Check must be submitted three years from the approval date indicated above.
5. When the study is completed, a Study Closure Form must be submitted to the IRB.

All of the above-referenced forms are available online at http://protocol.gsu.edu. Please do not hesitate to contact the Office of Research Integrity (404-413-3500) if you have any questions or concerns.

Sincerely,

John Weber, IRB Member

Table 1: Parental Stress Scale Raw Scores

Participant	Pre-PSS	Post-PSS	Percent Difference
1	25	23	-8.00%
2	40	27	-32.50%
3	43	27	-37.21%
Mean (SD)	36 (9.64)	25.67 (2.31)	