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Abstract

Several studies have documented the difficult experience of raising a child with a developmental delay (DD; DeGrace et al., 2014) but the majority of research has focused on non-Latinx White families and their experiences in childrearing and interacting with service providers (Hayes & Watson, 2013; Blanche et al., 2015). Additionally, stigma associated with mental illness and DD disproportionately affects Latinx communities (Burke et al., 2019). Familism plays a unique role among families of Latinx backgrounds (Moore, 1970; Coohy, 2001) and may act as a buffer to caregiver mental health. The current study aims to (1) determine the association between affiliate stigma and parenting stress among Latinx parents of young children with DD and (2) test whether familism moderates the relationship between affiliate stigma and parenting stress. Results revealed that the relationship between affiliate stigma and parenting stress was strongest in caregivers who reported low levels of familism, suggesting that familism may act as a buffer. More research is needed to further unpack the protective factors of familism on caregiver mental health.

Keywords

latinx families, children with developmental delays, autism spectrum disorder, familism, parenting stress

Developmental delay (DD) is broadly defined as a delay in physical, cognitive, communication, social, emotional, and/or adaptive development that occurs in children through age nine (IDEA, 2004; McIntyre et al., 2021). Caring for a child with a DD impacts both caregivers and family members (Estes et al., 2009; Herring et al., 2006; Mercado et al., 2020). Raising a child with a DD results in greater caretaking demands compared to children not diagnosed with a DD (Ashworth et al., 2019; Baker et al., 2003). Numerous studies indicate that caregivers of children with DD are at higher risk of experiencing anxiety, depression, and stress compared to caregivers of children with no DD diagnosis (Neece et al., 2012; Neece et al., 2019; Scherer et al., 2019). Distress levels among racial and ethnic minorities may be greater compared to non-Latinx White individuals because of cultural beliefs and values (Long et al., 2015). Research has also found that Latinx children with DD are four times more likely to reside in the home into adulthood as compared to non-Latinx White peers (Blacher & McIntyre, 2006) resulting in greater caregiving toll over the lifespan.

A DD diagnosis may be overwhelming for Latinx caregivers—a population that may have limited or stigmatized knowledge of mental health disorders due to the barriers unique to this group (Bauer et al., 2010; Blanche et al., 2015). DuBay et al.

(2018) highlight how Latinx families expressed limited knowledge of and exposure to DD in their home countries and these children are often treated as outcasts. They report that criticism (of mis-parenting or the parent causing the child's delay) from close friends or family was a clinically significant stressor for caregivers. Although there is limited and mixed information on the mental health of Latinx parents of children with DD (Hickey et al., 2021), the literature shows evidence of elevated levels of distress and pathology among Latinx caregivers of children with DD (DesChamps et al., 2020; Long et al., 2015; Mercado et al., 2020; Neece et al., 2019;).

While numerous articles have explored the impact of having children with DD in non-Latinx White caregivers (Blanche et al., 2015; Hayes & Watson, 2013;), the literature on the experiences of Latinx parents with children with DD is limited, with only a handful of articles exploring the caregiving experiences of this unique population (Blanche et al., 2015; Mercado et al.,

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2020). Arguably, the experiences of caregivers from Latinx/Hispanic background are culturally different to that of non-Latinx White caregivers (Blanche et al., 2015). As the largest growing ethnic group in the United States (CDC, 2015), it is important to understand the roles that stigma, and familism play on parenting stress to meet the culturally appropriate needs of this group.

Stigma Among Latinx Communities

Multiple studies have identified stigma towards DD and mental health disorders among Latinx communities as a key barrier to seeking and receiving mental health care (De Silva et al., 2020; DuBay et al., 2018). Risk factors for higher rates of stigma include parent nativity, number of children with developmental disabilities, severity of the developmental disability, and family structure (Zuckerman et al., 2018).

Affiliate stigma refers to caregivers, family members, or friends of an individual with a mental illness or DD that may internalize public stigma about the mental illness or disability (Mak & Cheung, 2008). One study found that high levels of affiliate stigma among Latinx caregivers with children with DD were associated with higher levels of anxiety and depression (Mercado et al., 2020). The prejudicial beliefs from family members and close friends have been found to contribute to caregiver stigma among Latinx populations (De Silva et al., 2020), given that family members often comprise most of the social support systems in these communities (DuBay et al., 2018). One study reported that higher levels of perceived social support among this population was associated with lower levels of anxiety and depression among Latinx caregivers (Mercado et al., 2020). Although stigma disproportionately affects Latinx communities compared to non-Latinx White individuals (Burke et al., 2019), there are factors embedded within the Latinx culture that can act as a protective factor for caregiver mental health, one of which is Familism.

Possible Mitigating Factor—Familism

Familism (*familismo* in Spanish) is a multifaceted construct that is a core component of Latinx culture (Moore, 1970). It can be expressed through attitudinal beliefs (Steidel & Contreras, 2003), behavioral manifestations (Calzada et al., 2012), and structural dimensions (Valenzuela & Dornbusch, 1994). Attitudinal beliefs are feelings of loyalty, solidarity, and reciprocity towards one's family members, while behavioral familism refers to the actions and behaviors that reflect those beliefs; such as shared activities and shared living. Structural familism defines the social boundaries (nuclear family vs. extended family) where behavioral actions occur and attitudinal beliefs develop their meaning (Valenzuela & Dornbusch, 1994). These concepts can be alternatively identified as *interconnectedness* and *support*.

Prior research has reported higher levels of familism among Latinx families as compared to Anglo families (Coohey, 2001; Sabogal et al., 1987). In a sample of Latinx parents of children

with autism spectrum disorder, families indicated that they relied heavily on other family members for help with child care, and they were also more likely to pool together finances, live together, and rely on each other as the main source of socialization (Estrada & Deris, 2014).

Within Latinx samples, higher scores of familism have been associated with higher maternal well-being (Magaña, 1999). In addition, Latina mothers who endorsed higher levels of familism and social support also engaged in less unhealthy (or abusive) parenting practices, as compared to Anglo mothers who relied mainly on friendships (Coohey, 2001). In a study of at-risk Latinx youth, cultural values and ethnic socialization were found to have a positive influence on adolescent mental health and increased prosocial behaviors (Berkel et al., 2010). Collectively, these findings suggest that familistic values may serve as a protective factor against certain parent and child characteristics and external risk factors.

However, studies have also found mixed results on the benefits of familism, most evident in the behaviors that reflect attitudinal beliefs, which may also result in Latinx parents being less concerned about symptoms of DD and, thus, less likely to seek diagnostic or therapeutic services (Mandell & Novak, 2005; Zuckerman et al., 2014). Family members may also influence such healthcare decisions by cautioning parents not to stigmatize their child (Rothe, 2005). Further, child rearing practices among Latinx families rely almost exclusively on family help for child care, creating possible role conflicts between parents and other family caregivers, primarily grandparents (Calzada et al., 2012) and siblings (Kao et al., 2011). Finally, higher rates of familism may be associated with higher isolation in families that are newly arrived and less established in the United States (Calzada et al., 2012).

The Current Study

Stigma associated with mental illness and DD disproportionately affect Latinx communities compared to non-Latinx White populations (Burke et al., 2019; Mercado et al., 2020). Higher rates of stigma in Latinx communities may also lead to the underutilization of mental health treatment (Rastogi et al., 2012), compounding its effect on primary caregivers given the research documenting the challenges involved in caring for a child with a DD (DeGrace et al., 2014). Latinx communities rely heavily on family support for the lifetime caregiving needs of individuals with DD which may impact the caregiver's mental health and quality of life (Herrema et al., 2017). Despite these risk factors, research has shown that familial social support has a powerful effect on Latina mothers and their parenting practices (Coohey, 2001). Collectively, these factors highlight the importance of understanding and characterizing the roles that stigma and familism play on parenting stress. By understanding the buffers to parenting stress, we can better support this population and address their mental health needs.

Overall, it is evident that several limitations persist in the literature on culturally-based coping mechanisms for Latinx

families. Familism has shown evidence as a potential protective factor that increases caregiver resilience, especially in families with multiple risk factors, such as poverty, language barriers, and caring for family members with DD. Yet there is still so much left to unpack in this multifaceted construct. Thus, the current study aims to address the following research questions: (1) What is the association between affiliate stigma and parenting stress in parents of young children with DD, and (2) Does familism moderate the relationship between affiliate stigma and parenting stress? We hypothesized that caregivers who experienced higher levels of affiliate stigma would report higher levels of parenting stress, and that familism would act as a buffer to reported levels of parenting stress.

Methods

Participants

Study participants were 28 Spanish-speaking caregivers (twenty-seven biological mothers and one grandmother) of young children (aged 3–5 years, $M=4.7$, $SD=1$) with DD who were part of a larger study examining the effectiveness of stress reduction and behavioral parent training interventions for this population. Families were primarily recruited through the Inland Regional Center a government agency in California that acts as a vendor of services for individuals with DD and other developmental disabilities in Southern California's Inland Empire region.

Criteria for inclusion were: (a) having a child ages 3 to 5 years with a DD who was receiving early intervention or early childhood/preschool special education through an individualized family service plan (IFSP) or individualized education plan (IEP); (b) having parent-reported concerns about their child's behavior (reporting some or many concerns about the frequency or intensity of child challenging behavior), and (c) being Spanish-speaking. Parents were excluded from study participation if (a) they screened positive for active psychosis, substance abuse, or suicidality (endorsement of screening questions for associated modules of the Structured Clinical Interview for DSM Disorders (SCID)-Research Version Non-Patient Edition) (First et al., 2002); (b) they were currently receiving any form of psychological or behavioral treatment at the time of referral (e.g., counseling, parent training, parent support group); or (c) their child had significant sensory impairments (e.g., deafness, blindness) or nonambulatory conditions that would necessitate the need for significant modifications to the study protocol.

Caregivers' mean age was 40.8 years ($SD=8.1$), and ranged from 25 to 72. All participants self-identified as Latinx and Spanish was their primary language. Caregiver education ranged from less than 7th grade to a 4-year university degree. Almost half of the participants (46%) had not graduated high school and 68% had a high school education or less. Most caregivers were full time homemakers (82%) and had a spouse or parenting partner in the home who worked at least part-time (90%). The remaining participants were separated (10%). A majority of families (79%) made less than \$60,000 per year,

and 43% made less than \$30,000. With regards to social services, 39% of families received supplemental security income (SSI) and WIC (Women, Infants, and Children) benefits, 43% accessed food stamps/CALFresh, and 96% received state funded healthcare (e.g., Medicaid/Medi-cal).

All children in the study had been previously identified by a community provider as having a DD or learning problem, the most common primary diagnosis was autism spectrum disorder (57%). Other primary diagnoses included general developmental delay (4%), speech delay (15%), genetic conditions such as Down Syndrome (14%), and other (10%). Eighteen children were male (64%) and ten were female (36%). Nearly all children (86%) were receiving services at the start of the study. Sample characteristics can be found in Table 1.

Procedures

Procedures were approved by the Institutional Review Board at Loma Linda University and were part of a larger, ongoing longitudinal study designed to provide in-person, group-based interventions in school and community settings to parents of young children with DD and problem behavior. The current study included a cohort of families recruited just prior to the COVID-19 pandemic. As part of the larger longitudinal study, all parents were randomly assigned to one of two intervention conditions: Behavioral Parent Training with Mindfulness (BPT-M) or Behavioral Parent Training with Psychoeducation (BPT-E). The current paper reports on 28 participants who participated in one or more of the 10 BPT telehealth intervention sessions during the COVID-19 pandemic and completed an online survey regarding their experiences during the pandemic. Parents in both intervention conditions received 6 weeks of an in-person, group-based stress-reduction intervention (either Mindfulness-Based Stress Reduction or psychoeducation) in February and the beginning of March 2020 prior to the stay-at-home orders associated with the

Table 1. Participant Sample Characteristics.

	Parent (n = 28)	Child (n = 28)
Mean Age (SD)	40.7 (7.6)	4.7 (1)
Gender (% Female)	100	36
Diagnosis (% ASD)		57
Receiving Services for DD (%)		86
Education (% with High School Diploma or less)	68	
Income (% less than \$30, 000)	43	
Social Services		
Supplemental Security Income (%)	39	
Medicaid/MediCal (%)	96	
CalFresh/Food Stamps (%)	43	
Women, Infants, Children (WIC, (%))	39	
Marital Status (% Married)	90	
Employment (% Employed Outside the Home)	18	

pandemic. The 10 weeks of BPT intervention were delivered online via telehealth due to the COVID-19 pandemic (see McIntyre et al., 2021 for more information). Families were contacted 6 months into the pandemic to complete an online battery of questionnaires centered on their experiences during the pandemic, emotional/behavioral measures, and questionnaires regarding familism, and affiliate stigma. Data was collected online via Qualtrics and analyses for the study were conducted using version 27 of SPSS. Modgraph was used to produce a graphical representation of the interaction effect (Jose, 2013).

Measures

All measures for the current study were administered in Spanish. When measures were not available in Spanish, study personnel translated the questionnaires into Spanish and then back translated the Spanish forms to check for accuracy.

Demographic Form. At the start of the intervention, caregivers completed a demographic form with information about parent and child characteristics (e.g., parent and child age, child diagnosis) and socioeconomic status (e.g., family income, employment, parent level of education).

Familismo Scale (Familism). In order to measure perceptions about the family unit, the Familism Scale (Steidel & Contreras, 2003) was administered to caregivers. This measure contains 18 items about family culture (e.g., A person should always support members of the extended family if they are in need, even if it is a big sacrifice), representing four main components of familism: (1) family comes before the individual, (2) family interconnectedness, (3) family support in times of need, and (4) familial honor. Caregivers endorsed items on a 5-point Likert scale from “strongly disagree” to “strongly agree.” Analyses for the current paper utilized the total score, with higher scores indicating higher endorsement of familistic values. Cronbach’s alpha was .83 for the overall scale, demonstrating a high internal consistency.

Affiliate Stigma Scale. In order to measure perceptions of self-stigma among caregivers of young children with DD, the Affiliate Stigma Scale (ASS; Mak and Cheung, 2008) was administered. This measure contains 22 items across three domains (cognitive, affective, and behavioral) that caregivers rated on a 4-point Likert scale from “strongly disagree” to “strongly agree.” Sample statements include, “I dare not tell others that there is a person with a developmental disorder in my family.” Analyses utilized the mean of the total score (ranging from 22 to 88), with higher scores indicating a higher level of internalized stigma. The instrument demonstrates high internal consistency with an alpha of .95 for the overall scale.

Parenting Stress Index—Short Form (4th Ed). To measure levels of parenting stress, the Parenting Stress Index-Short Form, Fourth Edition (PSI-SF; Abidin, 2012) was administered to

caregivers at several time points during the course of the intervention. Data from the PSI administered at time 2 (post-treatment) were utilized for the present study, as this was time point closest to the collection of the COVID battery of measures (within 3–4 months). The PSI-SF is a 36-item measure separated into three subdomains (parental distress, parent-child dysfunctional interaction, and difficult child). Each set of 12 questions generates a score that indicates level of distress resulting from personal factors that are directly related to parenting (parental distress), dissatisfaction in interactions with their child (parent-child dysfunctional interaction), and caregivers’ perceptions of their child’s behavioral characteristics that make them easy or difficult to manage (difficult child). Responses are captured through a 5-point Likert scale, from “strongly disagree” to “strongly agree.” Sample questions include, “Since having a child, I feel that I am almost never able to do things that I like to do,” and “My child rarely does things for me that make me feel good.” Internal consistency of the measure was good, reporting an alpha of .83 for the total scale (Haskett et al., 2006). The total score was used in analyses. Prior to interpreting scores, the PSI defensive responding score should be examined. This score is intended to identify participants who may be responding to questions in a defensive manner, affecting the validity of their score. For the present study caregivers with a score less than ten were identified and flagged as possible defensive responders.

Results

Prior to running analyses, data were checked for outliers. Data points outside of 3 standard deviations from the mean were considered outliers, no outliers were identified. One participant was flagged on the defensive responding scale (scored an 8), results were the same with and without the participant so they were included in the analyses. Assumptions were checked using descriptive statistics (see Table 2), skewness and kurtosis, and plots were inspected, no violations were identified.

Table 3 presents the correlations between the study variables. The correlation between familism and affiliate stigma indicated that caregivers who endorsed higher levels of familistic values also reported higher levels of self-stigma ($p < .01$). Correlations were not significant ($p > .05$) between the other variables of interest (perceived social support and parenting stress).

Table 2. Descriptive Statistics.

Variable (n = 28)	Min	Max	M (SD)
Stigma Total Score	22	66	33.86 (11)
Familism Total Score	41	80	59.75 (8.76)
Parenting Stress Total Raw	44	146	102.43 (26.57)
PSI – Clinical Level of Distress (%)			38

Table 3. Intercorrelations of Stigma, Parenting Stress, and Familism.

	Affiliate Stigma	Parenting Stress	Familism
Affiliate Stigma		.24	.51**
Parenting Stress			.34

**Correlation is significant at the .01 level.

Moderation by Familism

To investigate the moderating effects of familism on the relationship between affiliate stigma and parenting stress, a three-step regression analysis was conducted. First, a linear regression of stigma (IV) on parenting stress (DV) was run. The model was not significant ($p > .05$). Second, familism was added to the model. Although this increased the variance explained (26% to 34%) the model was still not significant ($p > .05$). Finally, the interaction term (stigma x familism) was added. In support of our hypothesis, the association between affiliate stigma and parenting stress was significantly moderated by familism ($p = .003$). (see Figure 1). The overall model accounted for 48% of the variance, $F(3, 20) = 5.32, p = .009$. (see Table 4). The graphical representation of the moderation relationship indicated that the association between stigma and parenting stress appeared strongest for families who reported low levels of familism, such that higher self-reported affiliate stigma was associated with significantly higher rates of parenting stress. The correlation between stigma and parenting stress among families who endorsed medium -to- high levels of familism was lower indicating that familism is likely acting as a buffer to parenting stress.

Discussion

The current study was conducted to investigate the effect of affiliate stigma on parenting stress and whether familism moderated the relationship between stigma and parenting stress. Previous research has focused mainly on non-Latinx White families and their experiences parenting children with DD (Blanche et al., 2015; Hayes & Watson, 2013). There also exists a dearth in the literature on Latinx cultural values and how these factors may influence caregiver mental health. Given the complexities of familism and elevated rates of affiliate stigma in Latinx communities (Burke et al., 2019; Mercado et al., 2020), a better understanding of the potential protective processes embedded in cultural values is of great importance.

In our examination of the relationship between stigma and parenting stress it was revealed that familism was significantly associated with stigma and parenting stress. The observed association was strongest in families who reported low levels of familistic values. In these families, results revealed that as self-stigma increased, families reported significantly higher levels of parenting stress. Whereas for caregivers who endorsed medium -to- high levels of familism, the association between stigma and parenting stress was weaker. Thus, familism may be acting as buffer between self-stigma and parenting stress.

Family support is vital when caring for a child with DD. Research shows that the mental well-being of family members is impacted significantly when raising children with DD (Blacher & Baker, 2017), with caregivers reporting higher rates of anxiety, depression, and a poorer quality of life (Herrema et al., 2017). Latinx caregivers of children with DD also experience higher rates of stigma based on several

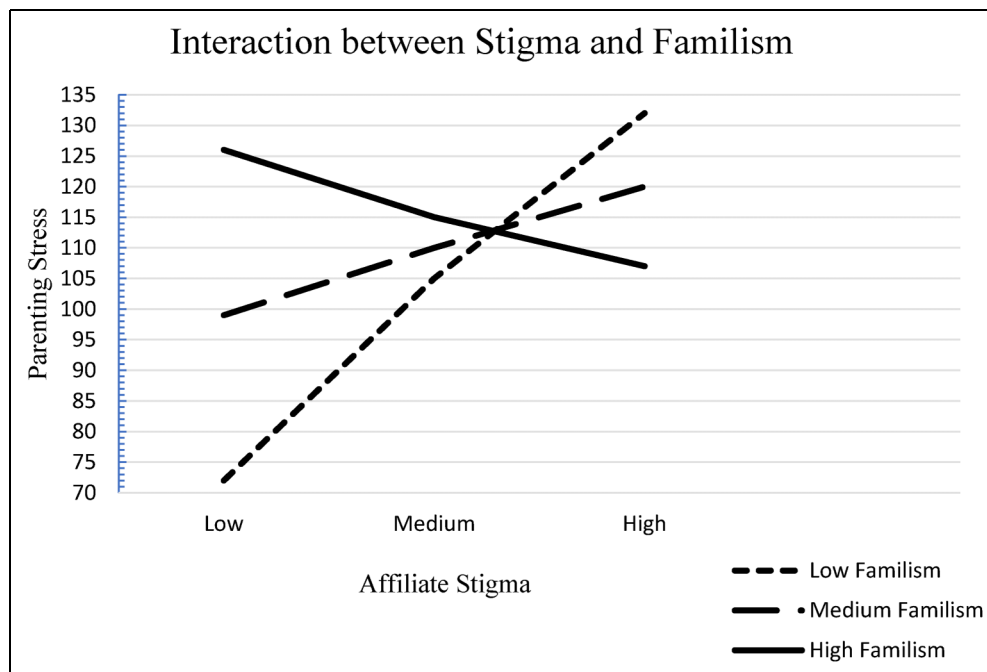


Figure 1. Interaction between stigma and familism on parenting stress.

Table 4. Multiple Regression to Examine Interactions of Affiliate Stigma and Familism with Parenting Stress as Criterion.

Variable	Coefficient			
	B	SE B	B ^a	t
Step 1				
Stigma	.63	.53	.26	1.18
Step 2				
Stigma	.12	.71	.05	.17
Familism	.85	.79	.31	1.07
Step 3				
Affiliate Stigma	12.78	3.67	5.17	3.48**
Familism	7.53	2.02	2.74	3.74**
Stigma x Familism	-.20	.06	-6.95	-3.49**

*significant at the .05 level, **significant at the .01 level.

risk factors, such as the number of children with a developmental disability and the severity of the disability (Zuckerman et al., 2018). Consistent with our findings, research has shown that familism may serve as a protective factor for parenting stress and maternal well-being (Magaña, 1999) observed in the strength of the association between stigma and parenting strength in families with low familism as compared to the lack of a significant association in familism with medium-high levels of familism.

Limitations

Our findings must be considered within the context of several study limitations. First, although this study utilized an understudied sample, there was no comparison group (e.g., non-Latinx White, English-speaking). Thus, it is unclear how specific our findings are to Latinx families of children with DD compared to families of children with DD more broadly. Second, the current study used cross-sectional data that was collected during a global pandemic, thus future studies warrant the use of longitudinal data in order to assess the direction of effect between familism and stigma. It is possible, and probably likely, that parenting stress also has an impact on perceptions of stigma and thus longitudinal data could contribute valuable information regarding this relationship.

Conclusion

Overall, the present study sought to expand the literature examining the role of familism in understanding the relationship between perceived stigma and parenting stress among Spanish-speaking Latinx caregivers of young children with DD. Although results should be interpreted with caution due to low sample size and the use of cross-sectional data, the association between stigma and parenting stress in caregivers who reported low levels of familistic values was stronger, highlighting the protective role that familistic values may have in Latinx caregivers. These findings have important implications for both

mental health prevention and treatment. Research has demonstrated that mental health concerns impact a caregiver's ability to effectively care for a child with a DD (Murphy et al., 2006); thus, it is imperative that researchers and clinicians explore all options when treating mental health disorders, especially in vulnerable Latinx populations who would benefit from culturally sensitive therapeutic resources. Additional research should be conducted utilizing larger sample sizes and collected longitudinally in order to assess the direction of effect between stigma and familism and its effect on parenting stress. In addition, comparative studies between Latinx and non-Latinx White families with and without children with DD would contribute valuable data on the group differences and improve the generalizability of findings to larger populations.


Declaration of Conflicting Interests

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