Perceived Stigma and Barriers to Accessing Services: Experience of Caregivers of Autistic Children Residing in Latin America

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ABSTRACT

Background: Relationship of perceived stigma and barrier to service access among Latino populations with autism in cross-cultural settings has not been fully explored.

Aim: The present study explored the relationship between difficulty accessing services and perceived stigma among caregivers of autistic children in Latin America. Additionally, explore contextual factors that better explain the perception of stigma when accessing services.

Methods and Procedure: Approximately 2500 caregivers from six Latin American countries completed an online survey. Descriptive inferential analysis and a pointbiserial correlation were conducted to understand direct relationship between difficulty accessing services and perceived stigma and to test their relationship. Added contextual factors contributing to this relationship were examined through a binary logistic regression.

Outcomes and Results: Barriers to accessing services predicted stigma. Contextual factors such as country of residence, frustration experienced by caregivers, gender of autistic child and challenging behaviours had higher odds of experiencing some form of perceived stigma.

Conclusions and Implications: These results suggest experiences with stigma to be heavily influenced by environmental factors such cultural differences which in combination with contextual factors could further increase the likelihood of perceiving stigma. When observing stigma within a social–cognitive approach, it is possible that a strong-held adherence to cultural norms, in addition to negative experiences (e.g., frustration) when accessing services, could be influencing caregivers perceived stigma.

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What this paper adds?

Research is heavily focused on studies conducted in high-income countries, often ignoring the experience of those living in low- and middle-income countries (LMIC). By focusing on caregivers residing in six Latin American countries, this study provides important insight into their experiences with perceived stigma and its relationship with barriers to accessing services. It is an essential addition to the body of research that focuses on Latino/as as it provides a wide, multicultural lens. It also suggests an interesting notion: experience of ASD in families is heavily influenced by environmental factors such as country of residence. Moreover, it allows for further understanding of the effect of gender, age of child, and frustration experienced by caregivers on perceived stigma and barriers to accessing services. When taking into consideration these factors on the relationship between unmet needs and perceived stigma, caregivers of adult and female children indicated higher levels of perceived stigma than the rest of the sample.

1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition which could cause lifelong disability (American Psychiatric Association, 2013; Baxter et al., 2015). Despite multiple studies attempting to further the understanding of ASD in the United States, the experience of ASD in Latin America is limited (Elsabbagh et al., 2012). The lack of systematic studies in Latin American countries leave a gap of knowledge concerning ASD among Latino/as. The closest comparison group are Latinx residing in the US, yet it is important to note that despite both type of Latino/as – U.S. residents and native born – sharing a similar cultural heritage, there are also differences such as a wider health inequality (UNICEF, 2016; World Bank, 2019). Keeping this in mind, when observing Latinx in the U. S., time and time again studies have indicated a lower or later likelihood of an ASD diagnosis (Christensen et al., 2016; Magaña, Lopez, Aguinaga, & Morton, 2013; Mandell, Listerud, Levy, & Pinto-Martin, 2002). In addition, Latinx experience a higher rate of misdiagnosis (Magaña et al., 2013; Mandell et al., 2002; Overton, Fielding, & Garcia de Alba, 2007; Wiggins, Baio, & Rice, 2006) or are more likely to be under-identified (Mandell et al., 2009; Pedersen et al., 2012). Not only do Latinx children and their families face these disparities in ASD diagnosis, once diagnosed they face a series of more significant barriers to accessing services (Morgan, Farkas, Hillemeier, & Maczuga, 2012; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Some of these barriers include a lack of insurance, low rate of education and health literacy poverty, structural barriers (i.e., length of appointment, transportation, etc.), low parental knowledge on ASD, and high levels of concern over public perception of ASD symptoms (Troxel et al., 2018; U.S; Zuckerman et al., 2014; Zuckerman et al., 2017).

As the current study focuses on Latino/as in Latin America, further issues can be identified in terms of the treatment gap. For instance, lack of political desire to implement reform and few mental health service providers and specialists to fully serve the population are some of the issues that perpetuate the treatment gap (Kohn et al., 2018). These external structural and systematic factors increase difficulty in accessing care for ASD in Latino populations, exacerbating an already confusing and overwhelming process (Zuckerman et al., 2014). Another factor that could further impact access to care and services is stigma towards those with ASD, hereinafter referred with identity-first terminology to avoid ableist language (Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2021; Cascio, Weiss, Racine, & the Autism Research Ethics Task Force, 2020). Yet, as an understudied area among Latino populations, little is known of stigma's effect on barriers to service access (Mascayano et al., 2016).

Stigma is the set of negative attitudes and beliefs held by an individual or society towards individuals deemed to have shameful characteristics (Corrigan, 2000; Corrigan, Roe, & Tsang, 2011; Mukolo, Heflinger, & Wallston, 2010). It encompasses prejudice, stereotypes, and discrimination (Corrigan, 2000; Corrigan et al., 2011; Mukolo et al., 2010) and is negatively associated with quality of life (Alonso et al., 2009) and access to mental health services (Corrigan et al., 2003; Brown et al., 2010; Fox, Smith, & Vogt, 2018; Jennings et al., 2015). Stigma is shaped by cultural differences (Mascayano et al., 2016) and experienced differently across cultural groups (Dietrich et al., 2004; Griffiths et al., 2006; Scior, Potts, & Furnham, 2013). While few studies have explored ASD stigma within Latino populations, some results suggest Latino parents of autistic children report high levels of stigma from family and community members (Blanche, Diaz, Barretto, & Cermak, 2015; Cohen & Miguel, 2018) or in connection to strong held adherence to expected cultural norms (Abdullah & Brown, 2011). Despite some studies focusing on culturally bound beliefs and its relationship with stigma (Cohen & Miguel, 2018), few have explored its relation to mental health conditions among Latino/as has (Mascayano et al., 2016), especially in ASD.

Research reports higher levels of stigma among caregivers of autistic children when compared to those of children with other disabilities (i.e., Intellectual Disability, physical disabilities; Werner & Shulman, 2013) and is exacerbated as the severity of symptomology rises (Zuckerman et al., 2018). High rates of stigmatization have suggested a positive association with social withdrawal, isolation, discomfort seeking care due to potentially negative reactions on behalf of the public and community, and unmet needs for ASD services (Mitter, Ali, & Scior, 2019; Zuckerman et al., 2018). Furthermore, caregivers of autistic children who reported higher levels of stigma also tended to endorse greater levels of unmet need (Zuckerman et al., 2018). However, much of the current literature examining ASD stigma in Latino/as has been conducted in the U.S. Therefore, the present study aims to explore and understand stigma presentation in Latino/as across Latin America.

1.1. Aims

The present study aims were two-fold. First, the study aimed to examine barriers (e.g., waitlist, lack of eligibility or availability, costs, limited information) to accessing services as a predictor of caregivers' perceived stigma. Understanding whether these variables predict stigma provides insight into future targets for sensitive interventions to reduce stigma and increase general knowledge and

awareness. The second aim of the study is to explore contextual factors that better explain the perception of stigma when accessing services. These factors included demographic variables such as country of residence, gender and age range of child and caregivers' perceptions such as autistic's individuals challenging behaviors and frustration experienced when accessing services. To the authors' collective knowledge, no studies have explored the relationship between stigma and unmet service needs across variables such as challenging behaviors exhibited by the autistic child, country of residence, age and gender of the child, and frustration of the parent in getting services. Utilizing a wide variety of national and cultural backgrounds can provide more insight on the general Latino/a experience of caring for an autistic child, especially with regard to stigma and unmet services.

2. Methods and Procedure

2.1. Sample Characteristics

The current study included a convenience sample of caregivers of autistic children and adults from six Latin American Countries (LAC): Argentina, Brazil, Chile, Dominican Republic, Uruguay, and Venezuela (Paula et al., 2020). Inclusion criteria were being at least 18 years of age and the caregiver of a child with ASD. Sample participants completed an anonymous survey. The total sample consisted of 2,965 caregivers. Excluded cases due to empty entries represented 16.2% of the initial sample, yielding a total sample of 2,484 caregivers. The missing data were assumed to be missing at random, and thus excluded.

2.2. Procedure

The present study utilized secondary data from a survey conducted by a group of specialists in each of the included countries who formed an alliance in 2015 called the *Red
Espectro Autista Latinoamérica* (REAL) to help deepen the understanding of ASD in Latin America. Recruitment was conducted through community support groups, service agencies, pediatrician offices, word of mouth, and Facebook groups. Participants completed an online survey (instrument) through google forms which took about 30 minutes to complete.

2.3. Instrument

Respondents answered the *Caregiver Needs Survey*, originally implemented in research by Daniels et al. (2017). The survey was originally developed by Autism Speaks to better understand the needs and challenges faced by families of autistic individuals (Daniels et al., 2017, Table 6). For this study, REAL translated the questionnaire into both Spanish and Portuguese; and back-translated it to the original language (English) to assure that the instrument's integrity was preserved. The survey included 26 questions divided within five sections that inquired about the experience of caring for an autistic, including challenges and barriers to services (Paula et al., 2020). Our attention was placed on caregiver's perceived stigma and experience when attempting to access services for their child.

2.4. Stigma

The survey included four questions targeted caregivers' perceived stigma by inquiring about experiences of being mocked, ridiculed, or negatively treated for having an autistic child. These four questions were in the form of statements: *I feel helpless for having a child with autism*, *I worry if other people would know I have a child with autism*, *Other people would discriminate against me because I have a child with autism*, and *Having a child with autism imposes a negative impact on me* (despite the present paper utilizing first-person language, the fidelity of the original language utilized in the instrument was preserved). Participants responded using a 4-point Likert scale ranging from *Strongly Disagree* to *Strongly Agree*. To conduct the Point-Biserial correlation analysis, all responses were included to calculate a mean score. Finally, to conduct the binary logistic regression, the items in the statements were dichotomized to permit assessing the presence or absence of perceived stigma.

2.5. Barriers to Accessing Services

The survey included six questions addressing caregivers' barriers to accessing services in the past twelve months due to: eligibility issues, lack of availability, waitlists, costs, lack of information, and a catchall category for any other difficulties experienced by families which do not fit under the previous groups. Caregivers could respond to all questions with *Yes, No,* or *I do not know*. These variables were considered as independent variables when conducting the binary logistic regression analysis. For the descriptive analysis, variables dealing with barriers accessing services were combined to reflect those caregivers who indicated agreement to at least one statement.

2.6. Frustration Accessing Services

One item inquired about caregivers' frequency of frustration in their effort to access services in the past twelve months. Caregivers could respond through a Likert scale ranging from 1-Never to 5-Always. For the binary logistic regression this variable was considered an ordinal independent variable.

2.7. Greatest Challenges

The survey asked caregivers to report the top three greatest challenges to caring for an autistic child. Among the options provided were challenging behaviors (e.g., self-injury, aggression, and tantrums), daily living skills (e.g., toileting and self-feeding), health problems (e.g., physical and/or mental conditions), sleep issues (e.g., trouble falling asleep and trouble staying asleep), diet/eating/ feeding difficulties, social interaction difficulties, repetitive/restrictive behaviors, communication difficulties, safety concern (e.g., wander and climbing), sensory issues, and one last category that enabled caregivers to report any other challenge not included in the previous items. Since caregivers were asked to choose the top three greatest challenges, the present study utilized the three most endorsed choices as independent variables in the binomial logistic regression analysis.

2.8. Demographic Information

The survey inquired about demographic information of the autistic individual. Pertinent to the current analyses were country of residence, gender (dichotomous with male and female options), and child's age (categorical, age ranges were divided among preschool aged, elementary school aged, adolescence, and adulthood). Demographic information were considered independent variables when conducting the binary logistic regression analysis.

2.9. Data Analysis

Once data was collected, it was coded and merged into a singular, multi-country SPSS dataset including data from all countries. Group comparisons between countries were conducted using chi-square tests, and a significance level of 0.05 was used to reduce the possibility of type I error. Statistical analysis included, first, descriptive statistical and cross-tabulations analysis were used to: characterize the present sample, identify the frequency of caregivers reporting positively to experiencing barriers to accessing services, perceived stigma, frustration in accessing services, and the top three challenging behaviors. Then, a point-biserial correlational analysis assessed the strength and relationship between perceived stigma and barriers to access services. Finally, binary logistic regression analyses were used to identify possible predictors associated with perceived stigma versus no endorsement of perceived stigma. The independent variables that were significant (p=<0.05) were considered predictors of perceived stigma. Predictors taken into account were country of residence, gender and age group of autistic child, frustration in accessing services, and top three greatest challenges as reported by caregivers.

3. Outcomes and Results

3.1. Sample Characteristics

Table 1 displays the demographic attributes of the sample. Children of participants were divided among age groups, gender of children, country of residence, and diagnosis of child.

Table 1
Demographic Characteristics of the sample

	Pre-school N = 867		Elementary N = 1089		Adolescents N = 264		Adults N = 264		Total N = 2484		x^2	□
	N	%	N	%	N	%	N	%	N	%		
Gender											17.725	**
Male	728	(84)	926	(85)	225	(85.2)	197	(74.6)	2076	(83.6)		
Female	139	(16)	163	(15)	39	(14.8)	67	(25.4)	408	(16.4)		
Country											116.96	***
Argentina	235	(27)	328	(30.1)	67	(25.4)	49	(18.6)	679	(27.3)		
Brazil	401	(46.3)	347	(31.9)	93	(35.2)	146	(55.3)	987	(39.7)		
Chile	53	(6.1)	130	(12)	44	(16.7)	26	(9.8)	253	(10.2)		
Dominican Republic	49	(5.7)	58	(5.3)	12	(4.5)	8	(3.1)	127	(5.1)		
Uruguay	110	(12.7)	153	(14)	37	(14)	32	(12.1)	332	(13.4)		
Venezuela	19	(2.2)	73	(6.7)	11	(4.2)	3	(1.1)	106	(4.3)		
Current Diagnosis											310.983	***
Autism/Autistic Disorder	664	(76.6)	622	(57.1)	112	(42.4)	139	(52.6)	1537	(61.9)		
Asperger's Disorder	45	(5.2)	201	(18.5)	89	(33.7)	90	(34.1)	425	(17.1)		
PDD-NOS	79	(9.1)	167	(15.3)	38	(14.4)	25	(9.5)	309	(12.4)		
PDD	79	(9.1)	99	(9.1)	25	(9.5)	10	(3.8)	213	(8.6)		
Insurance Coverage											23.111	**
Only Private	100	(11.5)	121	(11.1)	45	(17)	37	(14)	303	(12.2)		
Only Public	693	(80)	904	(83)	198	(75)	212	(80.3)	2007	(80.8)		
Both Private and Public	74	(8.5)	64	(5.9)	21	(8)	15	(5.7)	173	(7)		

Includes valid responses only, may not total 2484
*P < 0.05; **P < 0.01; P ***< 0.001

Table 2
Past 12-month barriers to accessing services by age group, gender, and country of residence of autistic children in Latin America

	Not Elegible			Services Not Available			Waiting List			Costs			No Information Available			Barriers to Accesing Services (Combined Variable)		
	N	%	x^2	N	%	x^2	N	%	x^2	N	%	x^2	N	%	x^2	N	%	x^2
			9.12			6.69			67.02***			16.94*			22.82**			10.06*
Pre-School	190	(22.4)		275	(32.4)		436	(59.3)		369	(43.4)		188	(22.3)		626	(79.2)	
Elementary	244	(22.9)		329	(31)		447	(48.2)		429	(40.2)		176	(16.6)		754	(75.9)	
Adolescent	72	(28)		87	(34.5)		95	(44)		105	(40.9)		68	(27.2)		178	(73)	
Adult	60	(22.9)		82	(31.3)		66	(32.5)		86	(33.2)		55	(21.3)		160	(70.2)	
Total	566	(23.3)		773	(31.9)		1044	(50.1)		989	(40.6)		487	(20.2)		1718	(76.2)	
Gender			.992			.894			1.15			.543			.913			.046
Female	90	(22.3)		125	(32)		163	(47.9)		159	(39.3)		79	(19.6)		287	(75.7)	
Male	476	(23.4)		648	(30.9)		881	(50.6)		830	(40.9)		408	(20.3)		1431	(76.2)	
Total	566	(23.3)		773	(31.9)		1044	(50.1)		989	(40.6)		487	(20.2)		1718	(76.2)	
Country			10.13			20.95*			96.34***			30.32**			54.02***			38.00***
Argentina	131	(20.4)		191	(29.8)		244	(43.4)		242	(37.5)		126	(20)		439	(72.2)	
Brazil	241	(24.6)		347	(35.4)		453	(56.2)		443	(45.1)		250	(25.6)		733	(82.6)	
Chile	66	(26.1)		72	(28.5)		99	(43.4)		102	(40.3)		43	(17)		166	(70)	
Dom. Rep.	36	(28.3)		50	(39.7)		58	(54.2)		58	(46)		12	(9.5)		94	(79)	
Uruguay	72	(22.2)		84	(26.3)		145	(51.8)		98	(30.4)		48	(15.1)		213	(70.5)	
Venezuela	20	(18.9)		29	(27.4)		45	(45.5)		46	(43.4)		8	(7.5)		73	(70.9)	
Total	566	(23.3)		773	(31.9)		1044	(50.1)		989	(40.6)		487	(20.2)		1718	(76.2)	

Reported values those who indicated agreement for each statement. Percentages are for within country, age and gender groups.

Includes valid responses only, may not total 2484.

* P < 0.05; **P < 0.01; P ***< 0.001

Table 3

Past 12-month access caregiver's perceived stigma by age group, gender, and country of residence of children with ASD in Latin America

	Feeling Helpless			Worrying Others Will Know			Others Would Discriminate			Negative Impact			Perceived Stigma (Combined Variable)		
	N	%	x^2	N	%	x^2	N	%	x^2	N	%	x^2	N	%	x^2
Age Group			25.91***			10.05*			.39			19.56*			7.67*
Pre-School	378	(43.9)		93	(10.9)		292	(34)		168	(19.6)		544	(62.8)	
Elementary	366	(33.9)		82	(7.6)		371	(34.4)		169	(15.7)		620	(56.9)	
Adolescent	97	(36.9)		16	(6.1)		85	(32.4)		44	(16.8)		153	(58)	
Adult	120	(45.6)		18	(6.9)		88	(33.7)		52	(19.8)		162	(61.6)	
Total	961	(38.9)		209	(8.5)		836	(34)		433	(17.6)		1479	(59.6)	
Gender			5.15*			1.22			.51			1.01			8.16**
Female	178	(44)		40	(9.9)		144	(35.6)		78	(19.4)		269	(65.9)	
Male	783	(37.9)		169	(8.2)		692	(33.7)		355	(17.3)		1210	(58.3)	
Total	961	(38.9)		209	(8.5)		836	(34)		433	(17.6)		1479	(59.6)	
Country			122.08***			10.98			17.53**			14.41*			57.71***
Argentina	197	(29.3)		44	(6.6)		227	(33.9)		111	(16.6)		374	(55.2)	
Brazil	506	(51.5)		100	(10.2)		338	(34.7)		198	(20.2)		660	(66.9)	
Chile	79	(31.2)		27	(10.7)		87	(34.5)		47	(18.7)		148	(58.7)	
Dom. Rep.	48	(38.1)		10	(7.9)		39	(31)		21	(16.7)		71	(55.9)	
Uruguay	113	(34.5)		21	(6.4)		127	(38.6)		48	(14.7)		190	(57.2)	
Venezuela	18	(17)		7	(6.6)		18	(17)		8	(7.6)		36	(34)	
Total	961	(38.9)		209	(8.5)		836	(34)		433	(17.6)		1479	(59.6)	

Reported values are the combined frequencies of Agree + Strongly Agree for each statement. Percentages are for within country, age and gender groups.

Includes valid responses only, may not total 2484

* $P < 0.05$; **$P < 0.01$; P ***< 0.001

3.2. Barriers to Accessing Services

As shown in Table 2, four of the six questions relating to difficulties in accessing services were experienced by more than 20% of caregivers. Caregivers of children within the pre-school age group reported waiting lists, backlogs, and other problems getting appointments (59.3%) and issues related to cost (43.4%) more frequently than the other age groups. In addition, caregivers from Brazil reported the highest rate of waiting to access services due to being put on a waitlist, backlogs, and other problems getting appointments (56.2%); while Uruguay reported the lowest rate of barriers to access services due to cost (30.4%). For the combined variable "Barriers to Accessing Services," 76.2% of caregivers endorsed at least one form of difficulty accessing services. There was a significant difference across age groups for this combined variable, with caregivers of children in the pre-school group reporting the highest frequency (79.2%, $x^2 = 10.06$, $p=<.05$), and across country of residence, with caregivers from Brazil reporting the highest frequency (82.6%, $x^2 = 38.00$, $p=<.001$). There was no statistical difference between gender for this combined variable ($x^2 = 0.050$, p > .05).

3.3. Frustration Accessing Services

Lastly, 37.5% of caregivers experienced frustration in their efforts to obtain services for their child. Cross-tabulation analysis indicated that while there were no significant differences between genders ($x^2 = 3.07$, $p > .05$), caregivers of adults (18+) reported the largest rate of answers endorsing frustration in efforts to get services for their child (41.5%), and caregivers of school-age children the lowest levels of frustration (35.6 %, $x^2 = 46.43$, p< = .001). Country of residence also showed significant difference, with Brazil reporting the highest frustration (46.3%), and Venezuela the lowest (13.3%, $x^2 = 98.58$, $p=<.001$).

3.4. Stigma

For the items related to perceived stigma, item *I feel helpless for having a child with ASD* had highest endorsement among caregivers from Brazil (51.5%) and among those who had an adult autistic child (45.6%, $x^2 = 25.91$, $p=<.001$). For the statement *Other people will discriminate against me for having a child with ASD*, the highest rate was reported by Uruguay (38.6%, $x^2 = 17.53$, $p=<0.001$) but no significant difference was found between age groups ($x^2 = .039$, p > 0.05). However, the item *Having a child with autism imposes a negative impact on me* was higher in caregivers of preschool age children (19.6%), adults (19.8%, $x^2 = 19.557$, $p=<.05$), and those residing in Brazil (20.2%, $x^2 = 14.41$, p > 0.05). Lastly, the statement *I worry if other people would know I have a child with ASD* had no significant differences across country but had the highest endorsement from caregivers of pre-school aged children (10.9%, $x^2 = 10.05$, $p=<.001$).

For the combined variable "Perceived Stigma," 59.6% of caregivers experienced some form of perceived stigma. In addition, there were statistical differences when considering gender ($x^2 = 8.16$, p=<.05), age group ($x^2 = 7.67$, p=<.05), and country of residence ($x^2 = 57.71$, $p=<.001$). Caregivers of females (65.9%), pre-school aged children (62.8%), and those from Brazil (66.9%) reported the highest rate of "Perceived stigma" (Table 3).

Table 4
Greatest Challenges of Caregivers in Latin America by age group, gender, and country of residence

	Social Interaction Difficulties			Challenging Behaviors			Daily Living Skills		
	N	%	x^2	N	%	x^2	N	%	x^2
Age Group			24.59***			6.13			10.05*
Pre-school	420	48.4		360	41.5		361	41.6	
Elementary	603	55.4		471	43.3		388	35.6	
Adolescent	169	64		91	34.5		88	33.3	
Adult	155	58.7		111	42		96	36.4	
Total	1347	54.2		1033	41.6		933	37.6	
Gender			0.46			6.77			7.66**
Female	215	52.7		179	43.9		178	43.6	
Male	1132	54.5		854	41.1		755	36.4	
Total	1347	54.2		1033	41.6		933	37.6	
Country			23.52***			3.85			10.09
Argentina	410	60.4		274	40.4		260	38.3	
Brazil	505	51.2		407	41.2		369	37.4	
Chile	151	59.7		113	44.7		77	30.4	
Dom. Rep.	57	44.9		57	44.9		57	44.9	
Uruguay	172	51.8		132	39.8		124	37.3	
Venezuela	52	49.1		50	47.2		46	43.4	
Total	1347	54.2		1033	41.6		933	37.6	

Includes valid responses only, may not total 2484

* P < 0.05; **P < 0.01; P ***< 0.001

3.5. Greatest Challenges

Table 4 provides information for greatest challenges. The top three challenges were social interaction difficulties (54.2%), challenging behaviors (41.6%), and daily living skills (37.6%). Social interaction difficulties showed significant differences between country of residence and age group, with Argentina (60.4%, $x^2 = 23.52$, p=<.001) and caregivers of adolescents (64%, $x^2 = 24.59$, p=<.001) having the highest rate of social interaction difficulties. No significant difference was found across gender. For challenging behaviors, no significant difference was found for country, age, or gender. Daily living skills were most endorsed by caregivers of females (43.6 %, $x^2 = 7.66$, p=<.01), but showed no significant differences for country of residence or across age groups.

3.6. Relationship between Barriers to Accessing Services and Perceived Stigma

A point-biserial correlation was run to determine the relationship between perceived stigma and difficulty accessing services. For this analysis, perceived stigma statements were included to calculate a mean score which transformed them into one continuous variable. There was a positive correlation between perceived stigma and difficulty accessing services statements, which were statistically significant in all cases (p=<.05).

3.7. Binary Logistic Regression

Table 5 provides results for the binary logistic regression to ascertain the effects of country of residence, frustration, gender, age, greatest challenges, and difficult accessing services on the likelihood that participants indicate perceived stigma when caring for an autistic child. A Bonferroni correlation was applied using all terms in the model, resulting in statistical significance accepted when p = .00625 (Tabachnick & Fidell, 2014). There were three standardized residuals with values between -2.530 and -2.684 which were kept in the analysis. The logistic regression model was statistically significant, X^2 (28) = 234.170, p=<.001. The model explained 15% (Nagelkerke R^2) of the variance in perceived stigma and correctly classified 65.1% of cases. Sensitivity was 80% and specificity was 43.9%. Positive predictive value was 67.1%, indicating that of all cases of caregivers indicating as having perceived stigma 67.1 % were correctly predicted, whereas the negative predictive value was 60.4%. Additionally, tests to see if data met collinearity assumption indicated that multicollinearity was not a concern since no tolerance values were less than 0.1 and no variance inflation factor (VIF) was greater than 10 (Hair, Black, Babin, & Anderson, 2010). Results indicate that residents of Chile (2.407), Argentina (1.825), Brazil (2.959), Dominican Republic (2.070), and Uruguay (2.500) times higher odds of exhibiting perceived stigma than those caregivers residing in Venezuela. When considering frustration accessing services, those caregivers who indicated feeling frustrated usually had 2.519 higher odds of experiencing perceived stigma whereas those who indicated always had 2.580 higher odds of experiencing perceived stigma when compared to those caregivers that indicated not knowing if they experienced frustration when accessing services. For difficulty accessing services, those caregivers that experienced difficulty due to lack of information had 1.660 times higher odds of experiencing perceived stigma than those who indicated not experiencing said difficulty. Caregivers of male children had .729 times lower odds of experiencing perceived discrimination than those that had female children, and those who did not perceived challenging behaviors (e.g., self-aggression, aggressive behaviors, and tantrums) as difficult had .689 times lower odds of

Table 5
Binary Logistic regression: Relationship between combined variables (perceived stigma and barriers to accessing services) and predicting factors

Variable Related to Hypothesis	B	SE	Wald	df	p	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
Country of Residence								
Chile	.878	.269	10.700	1	0.001	2.407	1.422	4.075
Argentina	.602	.247	5.909	1	.015	1.825	1.124	2.964
Brazil	1.085	.244	19.757	1	.000	2.959	1.834	4.774
Dom. Rep.	.728	.307	5.621	1	.018	2.070	1.134	3.778
Uruguay	.916	.263	12.107	1	.001	2.500	1.492	4.190
Frustration Accessing Services								
Usually	.924	.372	6.176	1	.013	2.519	1.216	5.220
Always	.948	.390	5.912	1	.015	2.580	1.202	5.538
Difficulty Accessing Services								
Lack of Information	.507	.141	12.838	1	.000	1.660	1.258	2.191
Gender	-.316	.135	5.505	1	.019	.729	.560	.949
Challenging Behaviors	-.373	.104	12.751	1	.000	.689	.561	.845
(Constant)	.241	.428	.318	1	.543	1.273		

Note: Country is comparing all mentioned countries with Venezuela, Frustration is for usually and always experiencing frustration accessing services compared to those who indicated not knowing if they experience frustration, and Difficulty accessing services is for yes comparing to no (those who indicated difficulty accessing services due to lack of information vs. those indicating no difficulty accessing services due to lack of information), Gender is for males compared to females, Challenging behaviors is for no compared to yes (comparing those who did not perceived challenging behaviors as difficult vs. those who did find challenging behaviors difficult to manage).

experiencing perceived discrimination than those who indicated this difficulty as challenging.

4. Discussion

Culture not only shapes the way parents and families conceptualize and experience ASD (Bernier, Mao, & Yen, 2010; Ravindran & Myers, 2012) but it also influences the way stigma is perceived (Mascayano et al., 2016). Through a multisite and multicultural sample, we explored self-reported experiences of perceived stigma to better understand the effect of potentially influential and moderating factors. For instance, in the current study, Brazilian caregivers reported the highest agreement with perceived stigma statements. If these results are explored within the framework of previous research, it can be observed that, compared to other Latin American countries, Brazil exhibits the highest rate of treatment gap (i.e., individuals who need treatment but do not receive it) at 78.1% (Kohn et al., 2018). Furthermore, Brazilian caregivers of autistic children report lack of support, postponement of diagnosis, emotional distress when receiving a diagnosis, financial hardships, and dire expectations of the future (Gomes, Lima, Bueno, Araújo, & Souza, 2015). Interestingly, in the present sample, Venezuelan caregivers showed the lowest rate of perceived stigma. Venezuela is experiencing a humanitarian crisis and complicated political situation with the shortage of basic needs such as food and medications, and human rights violations (Human Rights Watch, 2020). It may be possible that caregivers, and society at large, place concern on more pressing matters (e.g., food, safety) and thus push biases and negative stereotypes aside. This could explain the reduced perception of stigma within the current sample. Future research would benefit from further attempting to understand the multi-faceted factors associated with stigma, including protective factors and cultural differences.

Gender is one of the most studied variables in ASD research (Geelhand, Bernard, Klein, van Tiel, & Kissine, 2019; Halladay et al., 2015; Ratto et al., 2018). Yet, in terms of its interaction with stigma, no up-to-date research could be identified. In the present sample, gender was a significant factor in perceived stigma. For the combined variable, caregivers of female children reported almost 8% higher agreement to having experienced perceived stigma. This was also verified with the binary logistic regression results which indicated caregivers of male children were less likely to report perceived stigma when compared to caregivers of female children. If one views stigma within a social–cognitive approach, taking into account the interaction of stigma between individual and systematic factors (Abdullah & Brown, 2011), a different picture can be identified when comparing males and females. Latino cultures place value on societal norms. For Latino/as, the roles of *marianismo, machismo,* and *familismo* could be influencing stigma. Abdullah and Brown (2011) have pointed out how the role of women in terms of *marianismo* promote the idea of females having to endure suffering with dignity by being nurturing and self-sacrificing. Combined with *machismo*, the notion that males are stronger, and *familismo*, loyalty to family connections, females with a mental health conditions might experience a different set of hardships when going against cultural norms. In the current sample, caregivers of female autistic children might have a hard time when attempting to help their children navigate in a society with strong-held pre-determined cultural norms. The current results indicate the need for special consideration when assisting caregivers of female autistic children. Not only do they experience higher levels of perceived stigma but they also report feeling isolation and lack of understanding from others (Milner, McIntosh, Colvert, & Happé, 2019).

A more detailed analysis of perceived stigma in the present sample showed that the statement with highest adherence was feeling helpless for having an autistic child. This was especially true for caregivers of adult children. Autistic adults require access to services that target emotional, physical and mental health (Shattuck et al., 2020); yet as the individual grows older, caregivers of autistic adults find services to be either non-existent or to not meet their needs (Anderson, Sosnowy, Kuo, & Shattuck, 2018). As such, when being met with these barriers to needed services, caregivers could feel helpless and preoccupied by the lack of support offered to their children (Herrema et al., 2017). As one delves further to understand the experience of autistic adults, a somber picture emerges. It can be assumed that service limitations – or lack of – in addition to experiencing helplessness could explain, to some extent, why caregivers of autistic adults indicate lesser self-belief in parental ability to actively help their child (Crowell, Keluskar, & Gorecki, 2019). Additionally, caregivers of adult children in the current sample also reported the highest agreement to the statement: *Having a child with autism imposes a negative impact on me* was. This is noteworthy because previous studies have indicated caregivers of autistic adults report higher levels of concerns, depression, anxiety, stress, lower quality of life (Herrema et al., 2017), and poor emotional wellbeing (Pottie & Ingram, 2008). Thus, looking forward, it is important to be conscious of feelings of helplessness and worry when assisting caregivers of autistic adults. The current results reinforce the need to be tactful and aware of the struggle caregivers of autistic adults' face and provide them with added tools that could better assist them.

As has been mentioned, stigma is heavily influenced by cultural factors. The present study identified differences in perceived stigma adherence according to country of residence. For example, *I feel helpless for having a child with autism* was most endorsed in Brazil whereas *Other people will discriminate against me for having a child with ASD* was higher in Uruguay. It is important to note that in the Brazilian sample, caregivers reported having the most severe ASD cases which could indicate higher levels of emotional burnout (Paula et al., 2020), resulting in higher levels of helplessness. When considering discrimination against caregivers of autistic individuals in Uruguay, higher fear of discrimination could be explained by the country's false perception of cultural homogeneity where differences are ignored or not accepted (Cabella & Porzecanski, 2015). When considering the results of the binary logistic regression analysis, caregivers' country residence resulted in different likelihoods of endorsing at least one statement of perceived discrimination. Despite these results indicating the effect of cultural factors on the way stigma is perceived, it would be important to further understand how society at large contributes to its accentuation or diminution. In particular, considering that caregivers' frustrations can increase the likelihood of experiencing some form of perceived stigma. It is thus imperative to take into account caregivers' experiences when accessing services, with special consideration to cultural norms and values, to ensure diminished likelihood of stigma experiences.

Access to specific services among autistic individuals is needed across their lifespan (Cadman et al., 2012, Vohra, Madhavan, & Sambamoorthi, 2017), yet caregivers experience a plethora of issues when attempting to access said services (Nik-Adib et al., 2019).

Access to services can be even more cumbersome for those living in LAC (Montiel-Nava et al., 2020; Paula et al., 2020). The present study attempted to understand barriers to accessing services by inquiring about availability, waitlists, costs, and lack of information available. For caregivers in LAC, having an autistic child means scarcity of trained professionals (WHO, 2014), and scarcity of services (Montiel-Nava & Peña, 2008, Paula, Ribeiro, Fombonne, & Mercadante, 2011; Paula et al., 2020). In the current results, all countries showed above 70% of caregiver endorsement of experiencing some barrier to accessing services for their child. Furthermore, a significant percentage of caregivers reported not receiving any services (18%; Montiel-Nava et al., 2020) or experiencing frustration when attempting to access services (37.2%). Furthermore, those caregivers' who indicated lack of information available when accessing services were more likely to endorse some form of perceived stigma when caring for an autistic child. These numbers paint a concerning picture as results also indicate caregivers of preschool-age children reported the highest rate of barriers to accessing services (79.2%). This is problematic since early intervention, if started early, can positively impact the trajectory of symptom severity (Landa, 2018); thus limitation of services for younger children could hinder ASD prognosis.

As it has been observed, caregivers experience particular hardships when parenting an autistic child (Paula et al., 2020), not only in terms of social and structural factors, but also in dealing with problematic behaviors exhibited by their children (O'Nions, Happé, Evers, Boonen, & Noens, 2018). These behaviors can generate feelings of rejection and isolation in caregivers (Kinnear, Link, Ballan, & Fischbach, 2015). When inquired about perceptions of greatest challenges, caregivers of female children in the current sample reported the highest endorsement of *daily living skills*. When considering age group, caregivers of adolescents and adults reported *difficulty in social interactions*. These results could be explained by developmental stages and caregivers' expectations. Adolescence is a period characterized by a greater need for independence from caregivers with higher reliance on complex social interactions (Crosnoe & Johnson, 2011). Thus, one could assume caregivers of autistic adolescents would experience increased concern when seeing their children struggling with interpersonal relationships. For caregivers of adults, the results could be a reflection of factors studied in previous research by Herrema et al. (2017) which indicate caregivers of adult children worry for a future when they are no longer present, and their children will need to practice greater independence. As their child gets older, caregivers' expectations for more socially acceptable behaviors increase in an effort to ensure their child experiences a more independent livelihood (Herrema et al., 2017). This could result in increasing pressure for their child to fit in and function effectively in society. When considering gender, the effect of social norms and expectations among Latinos/as could be influencing caregivers' response to perceived challenges, particularly the roles of *machismo* and *marianismo*. As discussed, for females the role of *marianismo* places pressure to conform to traditional gender roles by being more feminine, nurturing, passive and composed (Nuñez et al., 2016). Consequently, higher endorsement to challenges with *daily living skills* among caregivers of female children may be attributed to concerns that, if unable to engage properly in self-care, their daughters would not efficiently fulfill their role as nurturers of others in the household.

When taking country of residence into account, differences emerge in terms of challenges reported by caregivers. For example, caregivers in the Dominican Republic and Venezuela reported the highest endorsement of challenges with daily living skills, whereas caregivers in Argentina reported difficulty with social interactions. It might be possible that in countries like Venezuela, where, as it has been mentioned, there is a humanitarian crisis (Human Rights Watch, 2020), caregivers would be more preoccupied with children learning basic skills to become more self-reliant. In the Dominican Republic, which has the lowest reported mental health expenditure of all countries included in the present sample, it could be assumed that caregivers are not being trained to properly assist their children diagnosed with autism. This is concerning given parent-led early intervention has been associated with improvement in daily living skills if targeted before age 3 (Bal, Kim, Cheong, & Lord, 2015). On the other hand, Argentina is the only country included in the sample that has institutionalized legal protection for individuals with autism (Montiel-Nava et al., 2020), and thus caregivers reporting issues with social interactions seem more in tune with a better environment where individuals can be more preoccupied with socialization issues. As with stigma, challenges experienced by caregivers seem to be highly moderated by culture.

This is one of the few studies that aims at understanding Latino caregivers experience outside the U.S., enabling current literature to gain knowledge and awareness of cultural differences within the Latino/a community when caring for an autistic child. The results of this study should be interpreted in light of some limitations. First, due to data collection taking place in six different countries, with different cultural, economic, and political backgrounds, not all confounding variables (i.e., socioeconomic status, background, protective laws for individuals with ASD) could be accounted for. Additionally, the survey relied on caregivers' self-report of diagnosis without corroboration of a documented diagnosis by professionals. Therefore, it is unclear whether all reported diagnoses were given by an ASD professional. Future research should address this limitation by ensuring documentation of the diagnosis utilizing medical records. The sampling process might have also incurred biases since most caregivers had a higher educational background (Montiel-Nava et al., 2020), potentially influencing their access to services given more knowledge, awareness, and higher SES. Moreover, when considering perceived stigma among caregivers, future studies could also take into account caregivers' ASD knowledge and level of acceptance of the condition. Especially when considering previous research indicating non-autistic individuals that are more knowledgeable and who received acceptance trainings showed less bias and stigma towards autistic individuals (Jones, DeBrabander, & Sasson, 2021).

5. Conclusions and Implications

This study assessed caregivers' experiences with perceived stigma, and its relationship with barriers to accessing services. It is an essential addition to the body of research that focuses on Latino/as as it provides a wide, multicultural lens. It also suggests an interesting notion: experience of ASD in families is heavily influenced by environmental factors such as country of residence. Moreover, it allows for further understanding of the effect of gender, age of child, and frustration experienced by caregivers on perceived stigma and barriers to accessing services. When taking into consideration these factors on the relationship between unmet needs and

perceived stigma, caregivers of adult and female children indicated higher levels of perceived stigma than the rest of the sample. To the authors' collective knowledge, the data gathered allowed for the largest and most representative multisite study assessing the Latino experience with perceived stigma and barriers to accessing services in a diverse, representative sample of the Latino population. This multi-cultural inclusion allows for a better understanding of the experience among Latino caregivers' concerning perceived ASD stigma, which may ultimately improve access to services and better advocacy programs for Latino individuals and their autistic child.

Authorship contributions

Please indicate the specific contributions made by each author (list the authors' initials followed by their surnames, e.g., Y.L. Cheung). The name of each author must appear at least once in each of the three categories below.

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Appendix A. Supplementary data

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