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Colombian parents of children with autism spectrum disorder: Perceptions, experiences, and expectations

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Abstract

Families play a critical role in supporting their children with autism spectrum disorder (ASD) and in advocating for their health and educational needs. However, many families around the world experience social, emotional, and financial difficulties, as well as challenges navigating various systems in search for the services and supports their children require. Colombia has made some recent strides in supporting the needs of families of children with ASD, but there is still concern among families that their children are not receiving adequate services. Thus, we were interested in learning more about what it was like to parent a child with ASD in Colombia. In particular, we focused on investigating the families' perceptions, experiences, and aspirations for their child with ASD by conducting focus group interviews. Four primary themes emerged from these interviews with Colombian parents, which included the impact of the disability diagnosis on the family, the systemic and societal challenges they faced, the strengths they saw in their child, and their future aspirations and expectations for their child. Implications for developing culturally responsive parent education programs are discussed.

Keywords: autism spectrum disorder; family; disability; parent; culturally responsive

Although families play a critical role in providing support to children with autism spectrum disorder (ASD), often they may experience uncertainty after their child receives a diagnosis of ASD (Kuc & Atasayar, 2019). Regardless of the country they reside in, many of these families experience social, emotional, and financial difficulties, as well as challenges with the medical and educational systems (e.g., Nealy et al., 2012). Compounding this situation, for many families in Latin American countries, is that there is often limited awareness about ASD and few government resources to address the need (Mercadande et al., 2009). Families in Latin American countries also report that they regularly face difficulties or delays in obtaining treatment due to a lack of available information where they live (Paula et al., 2020). Disability services are often provided through a country's health system, which can increase the challenges families encounter when seeking the supports needed. As an example, when families of children with ASD in six Latin American countries were surveyed about this, they frequently noted that structural barriers such as long wait lists, high cost of services, and lack of services contributed to the difficulties they faced (Paula et al., 2020). Similarly, a study in Brazil found that these obstacles began even prior to diagnosis, as many doctors were unable to give a specific diagnosis and sometimes blamed the parents for how the child was raised (Aguiar & Ponde, 2020).

Worldwide, families of children with ASD often indicate that they also face financial hardships, since often parents may cut back on their hours at work or stop working all together to provide the supports needed for their child with ASD (e.g., Bueno et al., 2012; Kuc & Atasayar, 2019). Often, families in many countries are expected to provide the educational services to their children with ASD, since they are often excluded from public schools or the demands imposed by the schools are too great (e.g., Puckett & McCoy, 2013). These families of children with ASD often face stigmatization, whether their child displays difficult behaviors or not (Broady & Stone, 2015). This stigmatization, real or perceived, also can impact how, where, and how often families participate in social settings (Werner & Shulman, 2015), which many families in Latin American noted tends to then increase their feelings of stress and isolation (Hartmann et al., 2018). Thus, it is common for families in Latin America, as in many other places, to go through a series of emotions, such as guilt, pain, and depression, as they learn about their child's diagnosis and begin to navigate informal and formal systems (Ráudez Chiong et al., 2017).

The present study took place in Colombia, which in recent years has started to make some inroads into gaining a greater understanding about ASD and providing supports for families and children with ASD (Tebar Fuquen & Díazgranados Beltrán, 2019). To start, Colombia signed the Convention on the Rights of Persons with Disabilities, which aims to guarantee the rights of individuals with disabilities (United Nations, 2006). In addition, the Colombian national legislation established a legal framework to protect individuals with disabilities and passed Ley Estatutaria 1618 de 2013 (2013), which is designed to ensure the rights of individuals with disabilities as well as outline duties of the government and society to improve services directed toward individuals with disabilities, and they also supported Decreto 1421 de 2017 (2017), which puts in place processes to guarantee quality education for all (Díazgranados Beltrán & Tebar Fuquen, 2018). Although these legal advances are positive steps, the reality of setting them into practice in Colombia has been challenging. For example, although there are some regulations and structural resources designed to support individuals with ASD in accessing health services, these individuals continue to have limited access to health services due to several factors including individually being socially marginalized (Rodríguez, 2018). It has also been noted that in Colombia, children with ASD tend to be diagnosed later than recommended due to lack of awareness and that there is a notable gap between the time a child is identified with ASD and the onset of receiving some type of supports and interventions (Talero-Gutiérrez et al., 2012).

Although the concept, definition, and much of the research related to ASD has its origins in the United States (U.S.) and Europe, other countries, like Colombia, have turned to this work as they begin to adapt the research to their own individual context by incorporating culturally appropriate practices, tests, and materials (Elsabbagh et al., 2012; Sarrett, 2015). The diagnostic criteria for ASD, as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013), is still the norm for now, even though not much is known on how aspects of ASD may be influenced by culture (Daley & Sigman, 2002). ASD is currently defined as a spectrum disorder, but earlier definitions included specific categories within the spectrum, such as Asperger's Syndrome, are still widely used in Colombia among professionals (Colombian Minister of Health, 2015). The prevalence of ASD is not well documented in many countries, with most information coming from the U.S. and Europe; thus, there is a lack of reliable population-based prevalence estimate published for most countries (Elsabbagh et al., 2012). However, the Colombian League of Autism estimated that, within Colombia, 1 in 110 children are identified with ASD, which is a lower prevalence rate than other nations such as the U.S., which has a prevalence rate of 1 in 59 (Baio et al., 2018).

Although research is emerging, there is still little research focused on how families in Latin American countries think and react when their child is identified with ASD. In Brazil, for example, families and mental health professionals have debated how best to respond to ASD. Families have argued that it is important to diagnose ASD early, so that evidence-based treatments can be provided to their children as soon as possible (Rios & Costa Andrada, 2015). Although there is an increasing awareness of ASD in Latin America, many do not have the infrastructure and capacity to meet many of the needs of families of children with ASD (Mercadande et al., 2009). Thus, families of children with ASD in countries with less established public services find themselves either needing to spend a great deal of time advocating for services for their children or providing the interventions themselves (e.g., Brezis et al., 2015). As a result of experiencing these types of situations, several Colombian families, who were looking for diagnostic services for their children who they suspected had developmental problems, organized, and began discussions in 2014 about establishing formal diagnostic services for children with ASD (Colombian Ministry of Health, 2015). By 2015, the Colombian Ministry of Health disseminated clinical guidelines for diagnosis and treatment of children with ASD (Colombian Minister of Health, 2015). The Colombian guidelines introduced a focus on early detection and providing comprehensive services. However, there is a scarcity of personnel in the health system prepared to diagnosis children with ASD, so few children are identified before the age of 10 years.

Notwithstanding advances in Colombia, the country's health care system is largely based on insurance and the family's ability to pay, which has created a fragmented system that does not necessarily meet the needs of children with ASD and has increased the costs of services for these families. In Colombia, only professionals that work in the health care system are permitted to diagnose children with ASD. Due to limited capacity within the health care system, ASD appears to be underdiagnosed in Colombia, which has led to great disparities and inequalities in access to diagnostic and treatment services (Moreno-Angarita, 2011). Even though Colombia has made some recent strides in supporting the needs of families of children with ASD, there is great concern among these families that their children are not receiving adequate services in either the health or education systems.

Although inclusive education for all students is mandatory, in Colombia there has not been special education in schools since 1994. Schools may have some personnel available to support children with disabilities, such as speech and language therapists and special education teachers, but the number of school-based personnel is limited. Thus, even though children with ASD are eligible to attend classes in the Colombian school system, in practice it is much more complicated. As part of Decreto 1421 de 2017 (2017), the principal and personnel providing supports work in collaboration with families and classroom teachers to develop an Individualized Plan with Reasonable Adjustments (PIAR). In practice, schools may then require that families provide additional supports including a one-to-one assistant. In addition, teachers in the Colombian school system need much more knowledge about ASD in general, as well as how to use appropriate strategies to support children with ASD in their classes, given that direct special education services within their classrooms are not necessarily provided (Rangel, 2017). Due to this lack of special education services provided within the Colombian school system, families that have the means to do so have historically enrolled their children with ASD in private institutions that can provide these supports.

Table 1
Demographics of Parents and Children (*n* = 20)

Characteristics	M
Parents' age	39.4
Parents' years of education	14.9
Children's age	8.7
	n (%)
Married or living with someone	11 (55)
Low income	10 (50)
Children's gender (male)	15 (75)

Given the situation that families in Colombia are currently facing, we were interested in learning more about what everyday life was like for these parents who had a child with ASD. In particular, we were interested in answering the following research questions: 1) How does parenting a child with ASD in Colombia impact the family? 2) What are the experiences of parents of a child with ASD in relation to support systems (e.g., education and family)? and 3) What are the expectations of Colombian parents regarding their children with ASD?

METHODS

Participants

As part of a larger study, participants were recruited from a public school in Bogota, Colombia after we received Institutional Review Board approval. The school was considered inclusive in that it offered education to children with disabilities, which in turn attracted high numbers of children with disabilities to the school. Children with disabilities were included in the general education classrooms; however, classroom teachers were not provided with sufficient resources to provide quality services. Children with disabilities at the school received special services from the health system, which included speech and language therapy and occupational therapy. The families of children with ASD at the school were invited to participate in a research study that focused on a parent education program that was conducted in their homes (Magaña et al., 2021). Families (*n* = 20) who participated in this larger study were then also invited to take part in focus group interviews, which focused on gaining a greater understanding of parenting a child with ASD. All except three participants in the focus group interviews were biological mothers of a child with ASD with the other participants consisting of two grandmothers and one father (we refer to all as parents in the paper). Given that the public school was one of the only schools in the city enrolling students with disabilities, the school attracted families from diverse socioeconomic backgrounds (see Table 1). In general, the parents who participated in the focus group interviews were well-educated, with most graduating from high school and 45% graduating from university with at least a bachelor's degree. Most of the parents (55%) were married or living with a partner and had a mean age of 39 years. Their children with ASD were primarily identified as male (75%) and had a mean age of 8.7 years (range 7 to 13 years).

Procedures

We used purposeful convenience sampling to identify the participants for this focus group interview study. All the parents in the focus group interviews had recently participated in a study that included a parent education program that focused on empowering Latinx parents of children with ASD (Magaña et al., 2021). Although the parent education program was developed and previously implemented in the U.S. (Magaña et al., 2020), the intervention was adapted to reflect the lived realities of families of children with ASD in Colombia (Magaña et al., 2019). The program consisted of two-hour sessions conducted at the parents' home by a promotora de salud (health worker) who is from the community and took place over 12 weeks. These parents were then asked about their interest in participating in one focus group interview to learn more about parenting a child with ASD in Colombia that would be conducted by researchers that they had not previously had direct interactions with during the parent education program implementation.

Focus Group Interviews. We invited the parents to come to a local university to participate in the focus group interviews. Each of the four focus group interviews were conducted by two bilingual interviewers. The lead interviewer followed a focus group interview protocol to ask the primary questions, while the second researcher took notes and asked follow-up probes for clarification. As an incentive to participate in the focus group interviews, we provided the parents with lunch. These focus group interviews allowed the parents to interact with each other and encouraged them to expand on each other's responses (Barbour, 2008). Frequently, focus groups are conducted with culturally diverse groups, since it can be empowering to the participants and provides an avenue for the initial explorations of a subject (Huer & Saenz, 2003). Focus group interviews also provide an avenue for the exploration of an individual's experiences and beliefs while interacting with others (Bragg, 2000). The interviewers were not acquainted with the parents, and parents were assured that their responses would remain confidential. Each focus group interview began with an overview of the purpose and format of the session. The interview was comprised of six questions with follow-up probes (e.g., What are the most important things we should know about your child?; We would like you to share with us the goals and hopes you have for your child.) and each lasted about an hour. Parents were actively engaged with us in lively conversations throughout the interviews, and there was no indication of any language misunderstanding between the interviewers and parents. The interviewers would periodically summarize the conversation and ask parents to confirm or clarify any of the summary points as needed. We created a spider diagram, a visual map that represented issues raised and helped to keep track of the discussions to ensure all parents had multiple chances to speak about the issues being discussed. The focus group interviews were audio recorded and professionally transcribed by a service that specialized in Spanish transcriptions.

Researcher as Instrument. Particularly in qualitative research, it is important that both the researchers' positionality (predetermined set of beliefs and perspectives) and reflexivity (critical reflections throughout a study) be mentioned (Trainor & Graue, 2014). It is through this self-reflection that researchers can begin to understand how one's own experiences influence and contribute to their positions and views (Milner, 2007; Trainor & Graue, 2014). Furthermore, as researchers open up about their positionality and reflexive practices, readers are then able to decide if researchers' bias may impact the discussions of findings and results. The first four authors, who reside in the U.S., conducted in-person interviews with Colombian parents to listen, interpret, and make meaning of their experiences parenting a child with ASD and navigating formal and informal systems to support their child. Our backgrounds are diverse (e.g., several first-generation Americans; one whose first language was Spanish; one born outside of the U.S.), but we all identified as Hispanic, bilingual women. Although none of the us had direct connections to Colombia, most of us had extensive experience living and/or working in other countries. We brought with us a Western worldview with a strong frame of reference influenced by the education and medical systems in the U.S., which we each have participated in through various roles such as students, educators, therapists, and mothers. Thus, our frame of reference was frequently subjected to critical analysis throughout our work in Colombia and during data analysis by employing an ongoing process of critical peer review and inspection (Merriam, 2009). The fifth author is a native Colombian, who lives and works in Bogota, and facilitated the research in a number of ways including recruiting the families, engaging with the other authors regarding considerations for cross-cultural differences, and reviewing the wording of the protocol and other language questions that came up during the research. She also vouched for our character, purpose of the work, and acted as a liaison, which assisted us in establishing trust and rapport with the families (Ojeda et al., 2011).

Data Analysis

Qualitative analysis procedures were used to identify the perceptions and experiences of the parents. We view ourselves as the primary instruments of the data collection and during data analysis used an inductive stance to obtain meaning from the parent responses (Creswell & Guetterman, 2019). In using this framework, we sought to explore and gain a deeper understanding of the families' perceptions and experiences of raising their child with ASD by using open ended questions. By using this framework, we were able to analyze the data without any preconceived notions, as we did not have a relationship with the families or educational systems in Colombia. Using a constructivist, grounded theory approach (Glaser & Strauss, 1999), we read and listened to interviews, wrote memos, coded data, compared and contrasted codes, negotiated codes, developed themes from the codes, and created matrixes of the identified themes (Maxwell, 2013; Saldaña, 2016). We did this work using collaborative online documents and research meetings, which allowed us to negotiate until we agreed on the final themes. Throughout this process, we continuously kept memos to track our thinking and give meaning to codes. We also identified parent responses that exemplified the themes and represented the range of perspectives the parents provided. To enhance the credibility of our findings we used a peer debriefer to critique, question, and analyze the findings. The peer debriefing process included inviting a colleague familiar with the research to question and discuss the findings, analysis, and conclusions (Mertens, 2015; Patton, 2015). A bilingual researcher who was not involved in the study, but who had expertise in qualitative methodology provided critical feedback at two points in the analysis. The peer debriefer first reviewed a sample of the transcripts, notes, and memos once the initial preparation phase was complete to check for clarity, bias, and accurate interpretations. At the end of the study, the peer debriefer provided feedback on the final themes by reviewing notes and represented quotes to provide an additional analysis of the overall trustworthiness and credibility of the findings. Although we were not able to conduct member check during the analysis process, a summary of the final themes that emerged was shared. All analysis was done using the Spanish transcripts with quotes later translated to English for dissemination.

RESULTS

Looking across the parents' responses related to their experiences and perceptions of parenting a child with ASD in Colombia, four primary themes emerged: (a) impact of the disability diagnosis, (b) systemic and societal challenges, (c) seeing child's strength, and (d) future aspirations and expectations. Examples of the parents' translated quotes for each of the major themes are included and identified with pseudonyms.

Impact of the Disability Diagnosis

Each of the parents described how ASD impacted their families. There were three subthemes that emerged as parents described the impact of ASD. The first was the intense emotional toll that the diagnosis had on them. Parents also described the discrimination that the diagnosis had created and how outsiders viewed their child. However, parents also explained they also had positive reactions to the diagnosis.

Emotional Toll. Most parents described the intense emotional toll receiving the diagnosis of ASD had on them personally. For example, Isabella stated:

> As a young pregnant woman, you visualize a future for your child, and you begin to create it. You construct a world for the baby, right? When [receiving the diagnosis], you take note that the world you constructed is going to be completely different.

Another parent, Monica, described, "I was on zero. I had raised two children well, and they were older. I had no idea he was a special needs child, much less a child with autism-because for me, I had never heard of that." Another parent shared that the diagnosis was a shock to her, and several others worried about their child's future. A grandmother described her fear for her grandchild during a different phase of life, such as when the child falls in love. "Another thing that I fear is if he falls in love. But the management of emotions is very difficult. Last Sunday I spoke to his mom and she said the worst thing that can happen to him is a broken heart." Families described the personal emotions that they felt and concerns about their child and the child's future and the difficulties that both they and their child may face.

Discrimination. During the focus groups several of the parents talked about how they felt that both their family and particularly their child with ASD were discriminated against in society. Salomé described how she understood the discrimination and worried about how others may view their child, which many of the parents also talked about. Salomé reported:

> The world is cruel, extremely cruel. I do not know if it is because the discrimination here towards people with a disability is terrible, and more so for a child or a person with autism. It is worse because, unfortunately, there are no physical characteristics that people can see to know that the child has a disability. Therefore, if this child is throwing a tantrum on the street or acting out of sorts or someone talks to them, they would say, "They are deaf, he is dumb, or ill-mannered."

By providing their own personal experiences with their children, parents were able to share their experiences of how others reacted. Their stories were examples of the difficulties and comments they endured when out with their children in public spaces.

Positive Reactions. There were also positive emotional reactions to the diagnosis of ASD noted by several of the parents. Several parents, such as Luciana, expressed love for their child regardless of difficulties they faced. As Luciana explained, "It was a blessing for us to have Samuel. We are all focused on getting Samuel ahead. We do not treat him as if he is different." For most, their child with ASD had become a primary focus of the family, as Valentina explained:

> My son is the most important person that I have right now. He is the reason I fight for things. We are focused on talking because it was not until recently that he started to communicate. We are doing well in therapy. Thank God he has made progress and is learning to fend for himself.

Each parent was able to offer a glimpse into the positive aspects of raising a child with ASD. While most expressed the love that they had for their child, they also expressed the "lucha" or struggle they engaged in to support their child and the child's needs.

Systemic and Societal Challenges

Parents described the barriers they experienced in Colombia with various support systems, specifically with therapy and the school system. They explained both systemic and societal challenges that their families faced. When describing systemic challenges, parents discussed how there were barriers to obtaining a proper diagnosis and therapies for their child, as well as barriers to getting educational services. Parents also described societal challenges, specifically, the stigmas that they faced from their families and communities.

Receiving a Proper Diagnosis and Therapy. Most of the parents talked about issues they faced with the medical community, including the high cost of the medical system. For example, Bianca talked about the high cost of medicine, while Karla, Isabella, and Luciana described the challenges of receiving a proper diagnosis. Salomé described the contradictory advice that she received from the therapists and her medical team. Specifically, in regards to her son's ability to speak and communicate himself, "the therapists tell me that it is a slow process and then other professionals are telling me that no, he is not going to be able to do it." Valentina also indicated that finding a therapist for her child was difficult. She noted, "That is the problem [finding a therapist] we have. It's very difficult to do anything here, that's why we are delayed." Sofia described her experience with doctors, "Here in Colombia, the doctors do not know what autism is, they have a fear of it. They know what it is called, but do not know more than that." Camila described additional difficulties with the Entidad Promotora de Salud (EPS), Colombia's government sponsored health care, "I have had a lot of difficulties with EPS. For me, it been awful, awful. That is because the health conditions of ASD are not well known, and it [the system] does not have the services that children need."

Overall, parents described challenges they had with the healthcare system and healthcare providers, especially with respect to obtaining the correct diagnosis, accurate assessment of their needs and receipt of appropriate therapeutic services.

Educational Services. Families described difficulties that they faced getting the best educational supports for their child. A few parents, Valeria, Salomé, Magda and Bianca, explained in detailed the difficulty in receiving educational services for their children. For example, Bianca explained:

> They are asking me to identify an assistant to be in the school, a shadow. He needs an assistant to help keep him organized and to make sure he completes his work, to complete activities. He is hyperactive, so then he has difficulty attending to a single task for some time, and can't be still for long periods of time, everything must be immediate.

Parents also spoke about how they were able to begin to obtain some supports to meet their child's need. Sofia indicated how together, school, therapy, and home can all work together to create positive results. Karla expanded on this and indicated that it was important to recognize how to best support her child, specifically when addressing her child's communication needs. Luciana described how they were able to find ways of supporting their child's academic and autism needs. However, other parents described their concerns about when and how much support to provide, as Isabella stated, "I don't know if I am intervening too much or not. I mean, I don't know if I am going outside the perimeter."

Parents described additional barriers they personally encountered with the Colombian educational system. Isabella addressed the systemic issues in the country, "The problem is not your child, it is the system. What happens here in Colombia, unfortunately, is that the teachers are not prepared to work with children with autism." Families described some of the obstacles they experienced receiving services in school, with teachers, and with supporting their child. Some parents appeared to be hopeful while others expressed frustration with the various systems.

Stigma. Several of the families also described the stigma that they faced from family and society in general. The parents described many personal stories of how others had directed comments about their children in public and how they reacted to those comments. Families shared similar reactions to one described by Isabella:

> When Carlos was in preschool, there was a parent reunion and one of the moms said, "Ah, you are the mom of the special needs child?" That lady killed me. I simply said, "Yes, I am the mother of Carlos." Then it was always the label, the label, "Oh you are the special needs child, the special needs child." Those kinds of

> things change your world. You begin to see the world in a totally different way.

Seeing Child's Strengths

When parents were asked to talk about what others should know about their child, the focus of their comments were overwhelmingly on positive attributes and much of the discussion was on the child's strengths. Overall, the parents listed several areas of strengths their child possessed, although the areas varied among the families. Some parents explained the child's independence in completing self-help skills as strength, and other parents focused on their child's academic abilities. Other areas of strength that were identified by many parents were their child's interests and personal traits.

Self-Help Skills and Routines. Several parents talked about their child's strengths and abilities to complete household routines and in learning self-help skills. For example, Valentina identified her child's ability to use the toilet independently, follow bath time routines, and request food or items as positive strengths. She explained:

> But that [going to bathroom independently] is a strength of my child because he is able to ask for things. You do not have to tell him to use the bathroom. He gets up by himself and goes independently to the bathroom. I tell him, "It's time to take a bath" and he takes off his clothes without me telling him.

Many parents focused on describing the different routines and household activities that their children were able to engage in independently. Sara explained that her child's interest in exercise was a positive quality, while Salomé identified her child's ability to dress themselves as a strength. Overall, they listed a variety of activities that they felt were important to their families.

Academic Strengths. Similar to describing their child's self-help skills and independence with routines, parents discussed what they perceived to be their child's academic skills and strengths. For example, Jimena and Salomé stated that reciting vowels was a strength. Salomé identified that her child's academic skills included letter and number knowledge, color identification and a strong visual memory. Another parent, Valentina, identified computing math facts and reading as a strength. Valentina noted that her son "already reads, writes, adds, and subtracts. . . . He is at the level of his peers." Other parents including Sara, Bianca, and Valeria stated that their child had a strong interest in technology and computers.

Personal Traits and Interests. Several parents centered their discussion on interest and personal traits the child possessed. They expressed their child's interests in motor activities or personal toys as an asset. For example, Jimena stated that her child enjoyed the arts: "He is very creative. He has artistic strength. He paints, draws, and makes things like the ones that are on [television] programs like Art Attack. They are drawings on the floor, and they form figures." Emilia and Valeria also identified that their children enjoyed music and riding their bicycles, while Sara explained her grandchild's interest in dinosaurs.

Several parents also talked about the many positive personal traits of their child, such as kindness or getting along with others. For example, Camila noted that her child's social skills were a strength, saying "She is very trusting. She likes to hug people. She does not shake hands, but she will hug and kiss and kiss. She is social. She will see a group of children arrive and will look to play [with them]."

Future Aspirations and Expectations

Parents were asked to talk about their expectations for their child with ASD. However, the conversations many times focused on the fears that they had for their children's future, specifically addressing future personal and work opportunities. Another area of concern that was brought up when talking about the future was their child's lack of or limited communication skills and concerns about their child being able to fend for themselves. An area that all families expressed as important was for their child to become independent.

Fears for the Future. Parents described concerns about their child's future, specifically, how it related to their child's careers and what would happen after the parent died. As Isabella explained:

> I have depressive episodes [thinking about the future], even though I have made accommodations. One of the things is that [child] will not go to university. I mean, that kills me. That he will not be able to achieve things as others do, like becoming a working person.

Other parents talked about concerns about their own death and what that meant for their child. Parent shared how they worried about who would take care of their child, even in adulthood, if they were no longer able to due to becoming sick or dying. As Natalia stated, "For me, my thoughts are, hopefully I will bury him instead of him burying me."

Limited Skills. Most of the parents expressed concerns about their child's limited communication skills and the impact this would have on their future achievements. They also talked about difficulties their child had attending to information and fending for themselves. As noted by Isabella, "I am concerned about his social interaction, because he can communicate and knows how to communicate, but others do not understand him." Other parents, such as Valentina, Gabriela, and Sofia, also described the importance of their child continuing to develop their skills to have a more positive future. For example, Sofia described the difficulties her child had with attention and its impact on learning, "Well to pay attention. If there is something that does not interest him, he stops paying attention, for him to attend is very, very complicated." Other parents expressed concerns about their children's ability to look out for themselves and their children's well-being, for example their children's happiness.

Independence. Parents expressed immediate and future goals for their child, and several parents expressed the importance of their child's ability to become independent, both in their own personal lives and within the communities they resided in. Parents described many examples, such as hoping that their child would be independent enough to have a paying job or develop personal relationship. Other parents talked about the importance of the child being able to participate in their community, such as taking the bus or shopping. Monica, reflecting comments of many other parents, stated that she wishes "that in the future he can work, function in society." Parents expressed quite a bit of anxiety about their child's future when thinking about having them become independent. As Magda stated, "I tell him, son you have to learn how to live without me. This concerns me, that he learns how to be independent and confident." Other parents talked about the ramifications if their child did not become independent, like Salomé, who expressed concerns about her child being a burden on other family members.

Role of Education. Parents discussed that their goals and aspirations included that their children could attend school, including college, which would lead to independence. The important role that education played in preparing their child for the future was brought up by most parents. For example, Isabella stated, "My goal for Carlos is that he finishes elementary school, then high school, and our family's goal is that he goes to the university, to study whatever, but that he studies something." Another parent, Salome also talked about the importance of her child finishing college saying, "My goal is that she finishes her bachelor's degree. The goal is that she completes it so that she is trained in something. The goal is to be independent and have a job. Yes, achieve stability, so she can feel useful." In general, parents provided specific individual examples of their dreams for their child, but also commented on the specific factors that may provide challenges for their children to achieve these dreams.

DISCUSSION AND IMPLICATIONS

In this study, we examined perceptions, experiences, and expectations of Colombian parents of children with ASD. Overall, the findings provided a rich description of the families' experiences as they navigated various systems and societal expectations. Parents shared with us that they faced numerous complications that included a lack of services, lack of doctors who could diagnose children with ASD, and in general, a lack of understanding of ASD from family and strangers. However, the parents indicated that they did not feel defeated or discouraged, but rather continued to seek services, wanting resources, and wishing for positive future outcomes for their children with ASD regardless of the obstacles they were facing. These families, like many Latinx families, faced a number of systemic barriers (Hughes et al., 2008; Mueller et al., 2009) and lacked access to information that could impact their decision making (Burke & Goldman, 2018; Shapiro et al., 2004). Not surprisingly, these systemic barriers increased the stress that these Colombian parents felt, which aligns to how other Latinx families have indicated feeling during their own journeys (Burke et al., 2019; Rios et al., 2020). They tend to report experiencing more stress and noting that their children with ASD may make less progress then they could have due to these barriers (Wagner et al., 2005). These Colombian parents were cognizant of these consequences and talked about the need to advocate for change in their country regarding how their children with ASD received health and education services. They also talked about the importance of society needing to be more understanding and supportive of families with ASD.

It is important that all families are empowered to advocate for change, regardless of circumstances they may face in their country. One way to develop parents' knowledge and advocacy skills is through parent education programs. Parent education programs have become common in the U.S. (Burke, 2013) with many showing positive impacts on both the family and child with disability (e.g., Aceves, 2014; Hammond & Ingalls, 2017). Parent education programs can enhance parents' knowledge of disabilities, while also developing their advocacy skills (Magaña et al., 2019; Burke et al., 2019). These programs should also focus on assisting parents' understanding of how to access both health and educational services (Taylor et al., 2017). Thus, we recommend that parent education programs be tailored to the specific needs and context of Colombian families of children with ASD (Magaña et al., 2019). Developers of these programs should consider using the Ecological Validity Framework (EVF) in creating the programs, especially since in the U.S., Latinx families have benefited from programs that use this framework (e.g., Magaña et al., 2020). The EVF could work well in the Colombian context, since part of the purpose of the framework is to develop culturally sensitive programs that are attuned to the context of the participants (Bernal et al., 1995). The EVF, which is comprised of eight cultural domains (e.g., language, content, context), can be used to ensure that parent education programs are culturally responsive for families in Colombia. When designing these programs, we want to keep in mind that families also have their own aspirations and goals for their children, regardless of the limited resources that are available. Furthermore, families need to be engaged in co-constructing the programs, including asking questions about what they understand and know about the disability and services available, as well as their aspirations for the child, since this will facilitate buy-in.

Limitations

This descriptive study was designed to investigate the perceptions, experiences, and aspirations of families with of children with ASD in Colombia. Several limitations exist that should be addressed. Given the small sample size, generalizability is not possible. It would be impossible to claim that these findings are reflective of the perceptions and experiences that all families may have. Nevertheless, the results can help guide us on how best to meet the needs of many families in Colombia, who have had similar experiences, and develop supports that align with these realities. Another limitation that exists is that this group of families may not represent typical families. One factor that makes this group unique was that all the families had recently completed a parent education program. Given this background, they may have been more willing to participate, as they had already had experience working with professionals to enhance their own knowledge and advocacy skills. Finally, all the data collected were based on self-report; thus, there was no independent documentation related to the families' interactions with education and medical systems. However, their words reflect their lived experiences and how families of children with ASD perceived the impact of their interactions with these systems and society.

CONCLUSION

In summary, the findings of this study highlight the impact the child's disability had on these families in Colombia, as well as the systemic and societal challenges they experienced. In many regards, the emotional and personal impacts were typical of families in similar circumstances, regardless of where they resided. However, the families did face barriers that were unique to their circumstances, particularly related to navigating the educational and medical systems in their search for the services and supports their child needed within Colombia. As the families mentioned, they frequently encountered professionals, both educators and doctors, that were uncertain or unfamiliar with the disability itself and often put the responsibility for the support needed squarely on the families. Regardless of these experiences, the families overwhelmingly continued to have a positive outlook and focused on the strengths of the child. However, parents did express a need for more supports and understanding from both professionals and family members. Families also craved opportunities to network with other families of children with ASD but talked about how difficult it was to build these relationships given that they had infrequent opportunities to engage with others. Therefore, we need to look at how schools and agencies can support and structure engagement to assist families in building deeper relationship with other families (Rangel et al., 2020), which in turn can be beneficial for all.

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