

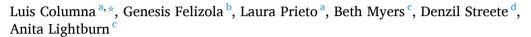
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# The experiences of Hispanic families of children with autism spectrum disorder regarding physical activity



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### ABSTRACT

Background: Researchers seldom focus on the services needed for Hispanic children with ASD, especially in regard to physical activity (PA).

*Purpose*: The purpose of this study was: (a) to explore why Hispanic families with children with ASD seek out and participate in PA, and (b) to describe the strategies and supports needed by Hispanic families of children with ASD to improve PA participation.

*Methods*: Participants in this descriptive-qualitative study were Hispanic parents of children with ASD (n = 9) who participated in one-on-one semi-structured telephone interviews. Interviews were transcribed and then analyzed using thematic line-by-line analysis.

Results: Two major themes emerged from the data: 1) Personal Responsibility and 2) "Every Day is a Different Challenge". Parents were motivated to engage in PA because of perceived health benefits for themselves and their children. Parents faced familial and external barriers that impacted their participation. Participants commented on the role of culture (e.g., customs, lack of family support after immigration) in the context of these barriers.

*Implications*: Further research is needed regarding culturally responsive PA interventions for Hispanic families with children with ASD.

## What this paper adds?

- The findings of this study indicate that Hispanic parents were motivated to engage in PA with their children with ASD, nevertheless these parents faced familial and external barriers that impacted their participation.
- The results highlight the importance of considering the role of culture when developing interventions for this population.
- Moreover, the findings of this study amplify the need to provide Hispanic parents of children with ASD with resources to become
  more physically active and strategies to teach their children to participate in various types of PA.

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## 1. Introduction

Physical activity (PA) has been shown to provide multiple physical, social, and emotional benefits for children with and without disabilities (Cardinal, Kang, Farnsworth, & Welk, 2015), including those with Autism Spectrum Disorders (ASD) (Pan, Tsai, & Hsieh, 2011). Children diagnosed with ASD may exhibit deficits in sensory processing, social communication skills and even delays in their motor skills (Staples & Reid, 2010). Research has demonstrated that when children with ASD are physically active their motor skills (Staples & Reid, 2010), communication (MacDonald, Lord, & Ulrich, 2014), and their socialization skills (Colombo-Dougovito & Block, 2019) tend to improve. Therefore, achieving and adopting active lifestyles is imperative for this population.

The U.S. Department of Health and Human Services recommends that children and adolescents, ages 6–17 years, participate in 60 min or more of moderate to vigorous PA every day (USDHHS, 2010), yet previous research has shown that children with ASD are not meeting these guidelines (Healy, Haegele, Grenier, & Garcia, 2017), tend to be less physically active than children without disabilities (Pan & Frey, 2005), and become even less active as they age (Todd & Reid, 2006).

Multiple factors have been identified as potential barriers to PA for this population. Some of these barriers include a child's disability label, difficulty accessing transportation, lack of programs, or a shortage of qualified personnel, among other factors (Obrusnikova & Miccinello, 2012). Over the last several decades, efforts have been made to attempt to overcome some of these barriers. For example, colleges and universities are training pre-service physical educators to better serve children with ASD in physical education and physical activity settings. Additionally, the use of technology can provide opportunities for some children to be active as they engage with movement-based video games (Edwards, Jeffrey, May, Rinehart, & Barnett, 2017; Obrusnikova & Miccinello, 2012). Importantly, the support of extended families and peers have been instrumental in promoting PA among children with ASD (Chang & Locke, 2016; Luther, Canham, & Cureton, 2005). As a result, interventions have been created to enhance PA and fundamental motor skills (FMS) of children, while giving parents the skills to promote active participation (Davis et al., 2017).

Parents from diverse racial and ethnic backgrounds, specifically Hispanic families, may have unique experiences and barriers when engaging their child with ASD. In the United States (U.S.), people of Hispanic origin are the nation's largest ethnic minority, comprising 18 % of the nation's population and are projected to be a majority in states such as Texas and California by 2050 (U.S. Census Bureau, 2017). Hispanic children (under the age of 18) are the largest cultural ethnic group in the U.S. comprising 5.6 % of the population (18.2 million). Despite the increase in the Hispanic population and the increase in the diagnostic incidence of ASD in the U.S., with 1 in 59 children being diagnosed with ASD (Baio, 2014), ASD is less commonly diagnosed in Hispanic children in comparison to non-Hispanic White individuals (Magaña, Lopez, Aguinaga, & Morton, 2013). Although there is no evidence indicating that ASD is dependent upon race, ethnicity, income, or level of education, the difference in diagnostic incidence between White and non-Hispanic White children might be due to the fact that Hispanic children are less likely to have health insurance, three times as likely to live in households that fall below the poverty line, and are likely to experience difficulty accessing health care (Flores & Tomany-Korman, 2008).

Research shows that compared to same age peers without disabilities, Hispanic children with disabilities tend to be less active, spend more time in sedentary activities, and are prone to obesity and other secondary health conditions (Broder-Fingert, Brazauskas, Lindgren, Iannuzzi, & Van Cleave, 2014; Corvey, Menear, Preskitt, Goldfarb, & Menachemi, 2016). Moreover, it has been established that secondary health conditions are common among individuals with ASD (Corvey et al., 2016). Recent evidence supports that active participation in PA is effective in ameliorating the side effects of physical inactivity (Aniszewski, Almeida, & Alvernaz, 2020).

Individuals with ASD, including those from a Hispanic background, experience multiple barriers to PA that will be explored in this paper (Ayvazoglu, Kozub, Butera, & Murray, 2015; Obrusnikova & Miccinello, 2012). As such, PA programs, interventions, and resources should be available to individuals with ASD and their families to improve their quality of life (Nichols, Block, Bishop, & McIntire, 2019). Hispanic families tend to engage in less PA when compared to White families (Arredondo et al., 2016). However, little is known about the PA patterns among Hispanic families of children with disabilities (Tybor et al., 2019). Knowing how Hispanic families of children with ASD perceive PA participation and having a clear understanding of the barriers these families experience when trying to engage in PA is necessary. This data can assist PA professionals in the development of PA interventions that meet the needs of Hispanic children with ASD and their families.

Thus, the purpose of this study was two-fold: (a) to explore why Hispanic families with children with ASD seek out and participate in PA, and (b) to describe the strategies and supports needed by Hispanic families of children with ASD to improve PA participation. To our knowledge, this is the first study that focuses on the PA of Hispanic families of children with ASD in the United States. This study aimed to answer the following research questions: 1) What are the perceptions about PA of Hispanic families of children with ASD? And 2) What are the barriers, if any, to participation of PA of Hispanic families of children with ASD?

## 2. Method

## 2.1. Research method

This study was situated in descriptive-qualitative methodology using a telephone interviewing approach (Cohen, Manion, & Morrison, 2011). One potential benefit of utilizing interviews is that this process allows for a deep understanding of people's attitudes and perceptions toward life events; in this case, the perception of Hispanic parents of children with ASD towards PA. One limitation of utilizing phone interviews is that the researchers do not have the opportunity to observe participants' facial and non-verbal expressions and consequently, researchers take the risk of losing some additional insight into what the participants were saying. However, Creswell (2016) asserted that telephone interviews are particularly useful when participants are located at some geographical distance from the

interviewer; as was the case in the current study.

## 2.2. Participants

Approval from the lead author's university Institutional Review Board was obtained. Purposive sampling was used to identify possible participants for the study in the form of a critical sampling technique (Cohen et al., 2011). When using a critical sampling technique, a group of participants is studied in order to gain knowledge that might have broader implications. For the purpose of this study, only those participants who met the inclusion criteria of being Hispanic parents of children ages 5–14 years with ASD (as their primary disability) living in the U.S. were included. Additional criteria included a parent report of an ASD diagnosis from a psychologist or by school personnel.

Flyers were circulated through nationwide listservs and ASD advocacy groups to recruit potential participants for this study. Although all guardians were invited to participate, all participants in this study were mothers. A total of nine mothers provided consent and participated in the interview process. Participants resided in five different states in the U.S. (Georgia, Florida, New York, Massachusetts, and Texas) and one participant did not report their state of residence. To protect participants' identities, pseudonyms were used for all participants. The average age of the children, who were all males, was  $10 \pm 2.60$  years. Of the nine mothers who participated in the study, two preferred to complete the interview in English and the remaining seven preferred to complete the interview in Spanish. Five families reported having an income of less than \$45,000 a year (Table 1).

## 2.3. Data collection

Data was collected using a demographic data sheet and an interview protocol. Interested participants reached out to the researcher through email and after it was determined by the research team that they met the inclusion criteria, a day and time for the phone interview was arranged. Prior to conducting the interview protocol, demographic questions about each participant's age, gender, income level, preferred language, education level, and type of employment were asked over the phone. These questions were answered by the participants and audio-recorded by the PI. We used semi-structured telephone interviews that involved verbal interchanges with the participants. By utilizing this process, we provided a medium for the participants to reflect on and speak about specific situations related to PA and their views regarding PA for their children with ASD. Each interview, which lasted from 60-90 min, was audiorecorded to ensure accuracy and content validity. Interviews were conducted in the preferred language of participants, Spanish (n = 7) or English (n = 2). All interviews were conducted by two bilingual researchers (Spanish and English). Both researchers conducting data collection (PI and third author) were present during each interview. The PI took the lead during the interview process and the third author was able to expand or ask for clarification as needed. During the interviews, participants were asked to share their personal and their children's experiences regarding PA, discuss their motives to participate in these activities and share their experiences regarding barriers, if any, that they experienced when trying to engage in PA. Sample questions included the following: (a) Why do you and/or your family engage or not engage in physical activities? (b) What concerns, if any, do you have involving and teaching physical activities and games to your child with ASD? and (c) What assistance do you need to enhance or maintain the PA participation for your family and child with ASD? Follow-up probing questions were asked based on participants' responses. At the end of each interview, participants were given time to express any thoughts they felt were missed during the interview.

Table 1
Demographic Information.

Participant	Parent Preferred Language	Child Gender	Child Age	Ethnicity	Child's Education	Location	Education of Parent	Social Economic Status
Maria	Spanish	M	9	Hispanic	Homeschooled	NY	Some University/ 2 years in University/ Associates	\$25,000-\$44,999
Sandra	English	M	6	Hispanic	Preschool, day care, head start	NY	Some University/ 2 years in University/ Associates	Unemployed (Under \$10,000)
Anna	Spanish	M	13	Hispanic	Public School	Tampa, FL	University Masters	\$45,000-\$74,999
Sophia	Spanish	M	12	Hispanic	Public School	Atlanta, Georgia	Some University/ 2 years in University/ Associates	\$25,000-\$44,999
Amy	English	M	8	Hispanic	Public School	Syracuse, NY	Bachelors.	\$45,000-\$74,999
Carla	Spanish	M	14	Hispanic	Charter School	Texas	Not specified.	More than \$100, 000
*Paola	Spanish	M	8	Hispanic	Public School	NY	Not specified	\$75,000-\$99,999
Juana	Spanish	M	10	Hispanic	Public School	Not specified.	Bachelors.	\$25,000-\$44,999
Elisa	Spanish	M	10	Hispanic	Charter School	Boston, Massachusetts	Not specified.	\$10,000-\$24,999

Note: \*Paola: Twins with ASD, both male.

## 2.4. Data analysis

Interview recordings were transcribed and then analyzed using a thematic line-by-line analysis (Merriam, 1998). The Spanish interviews were first transcribed in Spanish before translating to English. The second author, who is a bilingual researcher (Spanish and English) translated the Spanish interviews to English through the use of double translation (Marin & Marin, 1991). The double translation process included translation of the original Spanish transcripts to English. Next, the transcripts were sent to the first and third author, who were also bilingual, who translated them from English back to Spanish. The original transcripts were then compared to the translation to verify accuracy.

The parents' interview data were analyzed inductively by preparing the data (transcribing), reducing the data, and arranging data into themes, using NVivo 12 software to categorize codes into themes. Additionally, *in vivo* codes, which are selected text that are assigned labels using a word or phrase from the transcript, were created by the researchers, and then categorized using the NVivo 12 software.

Three of the authors independently read the transcripts and analyzed and coded the data independently from one another. The researchers then reviewed their analyses together to reach consensus regarding codes, themes, subthemes, and their descriptions. Following this step, the authors extracted and categorized themes from the data. In reducing the text, when researchers found revealing information, they were highlighted and coded with meaningful labels. This process led to the connection of patterns within categories resulting in the emergence of recurring themes. Codes that were conceptually similar were clustered together into thematic statements, thus, giving fundamental meaning to the experiences (Creswell, 2016). Once the themes were identified, supporting quotes for each theme were gathered, and these were translated from Spanish to English by two bilingual members of the research team. Lastly, themes were matched to supporting quotes retrieved from the transcripts to an external reviewer who examined the themes to verify they reflected the purpose of the study and corresponded with the research questions. This external reviewer was an expert in adapted physical activity and a qualitative researcher with over 25 years of experience.

## 2.5. Validation of the findings

To ensure trustworthiness and reduce subjective bias, several methods were used: (a) data analysis by multiple researchers, (b) evaluation of the data by an external reviewer and (c) member checking. The transcript data were analyzed individually by three researchers enabling triangulation of the data. We also provided the preliminary themes along with supporting quotes retrieved from the transcripts to an external reviewer. This external reviewer examined the themes to assure they reflected the purpose of the study and corresponded with the research questions. To ensure dependability of the findings and accuracy of the data, member checking allowed participants to read the transcripts of their interviews to clarify or better explain their views and beliefs.

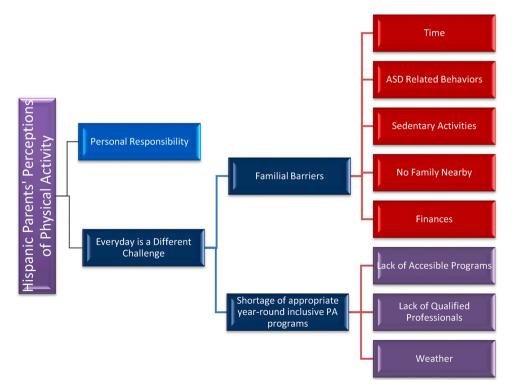


Fig. 1. Visual of Themes and Subthemes.

## 3. Results

Two major themes emerged from the data: 1) Personal Responsibility and 2) "Every Day is a Different Challenge". These themes are supported by several subthemes (see Fig. 1).

## 3.1. Theme 1: personal responsibility

Participants shared their motives for participating in PA. One such motive was that they believed it was their sole responsibility to teach and model healthy lifestyles to their children. This theme is supported by the following subthemes: 1) needing to stay healthy for their children and 2) finding physical and recreational activities.

## 3.2. Subtheme 1: needing to stay healthy for their children

All parents primarily indicated a desire for perceived health benefits that accrued from their own PA participation, motivated not only by their ability to provide long-term support for their child, but also to serve as models for their Hispanic children with ASD. For example, Sandra mentioned that because of her age and as a mother of a child with ASD, she needed to stay active so she could be there for her child when she gets older: "I do a lot of research and I know that your mind and your body are connected. I must be healthy because I'm going to be 50, 55, or 60 years old." Similar to Sandra, Paola made reference to her age and her priorities to be healthy so she could take care of her child with ASD.

Sophia shared the same sentiment of being healthy for her own wellbeing and for her children. Sophia summarized this sentiment about the benefits of PA, explaining that it is a parent's responsibility to teach healthy lifestyles to their children. She added,

[Parents] can teach children that it's important for them to stay healthy... but they don't give it the importance that it needs. For them, education is math, science, language arts...The rest can help you in any profession, but physical activity helps you as a person.

Parents perceived benefits that could be obtained from PA participation, which included: obesity prevention, social benefits, and overall health benefits. Parents recognized that their children might not be as physically active as other children without ASD, yet they would like to keep promoting PA. Maria, whose nine-year old son is homeschooled explained, "I don't want him to spend the whole day in front of a TV, in front of a computer...It is very important for him to be physically active. There's no room for discussion about that in this house." Six out of the nine parents indicated that they tried to encourage PA because they were afraid their children would become obese. Sandra also commented, "I am a believer in having a lot of physical movement and engaging different parts in your brain. They thought he was never gonna walk. But I was very determined to get him on his feet." Sandra believed that engaging her son in routine PA at an early age helped her son to achieve some of his developmental milestones.

## 3.3. Subtheme 2: finding physical and recreational activities

When parents expressed that they valued being physically active, we inquired about their child's participation in different types of PA. Seven parents shared unstructured activities. Sandra, for example, indicated that engaging her child in PA is not always an easy task. She explained, "We take him out across the street, we go to the park. We make him go up steps, if it's too cold we go in the hallway, we live in a building. Anything to get him moving." Although seven parents shared unstructured participation in PA, two mothers indicated that they found structured community programs that welcomed their children. Paola, a mother of two children with ASD, shared her experience with a CrossFit program targeted for children with ASD, "We found CrossFit...we read of exercises that can be good for my kids with autism...we were looking for things that they can be successful at." For this mother, CrossFit was valuable not only because it provided a welcoming environment, but also because there were other children with ASD was very encouraging to her.

Carla, on the other hand, enrolled her child in lacrosse because it provided a social outlet for her son to interact with other children without disabilities. She commented, "He goes to lacrosse...my goal is not for him to come out as a lacrosse player, but I want him to go through the experience and get socially involved with other kids." Regardless of the selection of unstructured or structured activities, all parents voiced that seeing their children playing or participating in PA was a rewarding experience. Maria explained that she was excited because of her child's participation in PA: "Like any other parent, it's happiness of course...you want your kids to reach milestones, reach independence." All parents in this study found the benefits of PA motivated their child and themselves to participate.

## 3.4. Theme 2: everyday is a different challenge

This theme describes the issues parents face on a daily basis when trying to provide and create PA opportunities for their families. Moreover, families shared several barriers they faced when attempting to participate in PA, and in some cases they shared strategies to overcome such barriers that must be considered when trying to implement programs for this population. This theme also illuminated the following subthemes: 1) familial barriers and 2) shortage of appropriate year-round inclusive PA programs.

## 3.5. Subtheme 1: familial barriers

Several familial factors impinged on the participation in PA among the families in this study. Five main familial barriers were identified in the data: a) time, b) ASD related behaviors, c) preferences for sedentary activities, d) no family nearby, and e) finances. Parents shared how these barriers affected their families in the pursuit of PA opportunities and in some cases, families voiced strategies

they used or wished were available to overcome barriers.

#### 3 5 1 Time

Because of work obligations and having to care for the rest of the family, parents expressed that a lack of time was a barrier to engaging in PA. Sophia recalled that when she was married and a stay-at-home mother, PA was a priority for her family. However, after her divorce this changed: "I don't really have the time...if we do a physical activity it's a weekend. On weekdays, we get home at like 7 o'clock at night. Then it's time to eat, bathe, and go to bed." Sophia tried to incorporate PA during weekends, however, for other parents weekends were not an option. According to Juana weekends were her only time for her to rest: "Some parents wouldn't even want to get up on a Saturday when they're on their day off and take their child to play baseball." In addition to work schedules and other obligations with their children, Carla complained about the amount of work her children received from school, saying, "The school gives too much homework and kids basically have no social life." All parents indicated that they tried to be part of their children's activities, including PA, as much as possible.

## 3.5.2. ASD related behaviors

Participants mentioned their child's ASD related behaviors as a primary barrier to PA. Parents explained that their children wandered around or did not like to engage in PA. For all parents, sensory or behavior issues affected their participation and their opportunities to interact with others. As Sophia explained, "Every day is a different challenge... When he began [to play baseball] ...he didn't want to do anything...when he started to sweat, he didn't want to do anything else because he was sweaty...he stopped."

Similar to Sophia, Sandra indicated that her child's behavior also made it difficult to predict what he would do: "Some kids enjoy climbing a ladder or stairs [and it is fun], but for [child's name] it becomes a chore, an exercise, a task, so it's not pleasant." For Sandra, knowing how to motivate her child to enjoy PA was a daunting task. Other parents agreed. For instance, Sophia discussed that her son's needs often create a barrier to his participation engaging in PA. For her, trying to convince her child to try a new bike was very difficult and she struggled getting him to try new activities: "The bike he has is not his size, but he does not want another bike...he says that's the one he knows how to ride." Because of their children's disability and being afraid of what other people might think of them and their children, three parents in the current study also avoided public places and opted out of pursuing more structured activities, which usually translated into being involved in more sedentary activities. Carla commented, "I think a lot of parents don't put their children in a special education program for sport or physical activities because they're worried other people might think or say things about them."

## 3.5.3. Sedentary activities

Sedentary activities such as watching tv or playing video games were mentioned as one of the reasons for not engaging in PA. Children were drawn to technology, and in some cases parents used the technology to keep their children calm. When asked why they think children are spending too much time using electronics, all parents indicated that their children gravitate to electronics. For Maria, preferences for technology is also in part due to the sedentary lifestyles of families living in the US. She mentioned, "I think it's the sedentary life that people lead here in this country... That's not a diagnostic thing." Sandra confirmed the statement voiced by Maria by sharing, "Home is boring. Home is where you come to relax. Home is not where you want to work out and sweat and push yourself and do lunges and push-ups." Despite the sedentary lifestyles families experienced, Sandra tried her best to promote PA. Sophia also explained that she tried to keep her son away from electronics and being secluded in his room, "I have to convince him in a way that he leaves the room... That's his habitat...I'm worried he really likes being locked up." Parents articulated that electronics are the easiest options for families to keep their children calm. Anna commented, "It's easy... you give a tablet to a child with autism and that's the easiest thing to raise... They're not going to bother you at all... and it's going to be the best kid to take care of." Four parents indicated that they used technology as a reward for PA. Carla, for example, let her son use electronics at home, but she set rules in terms of the time her child could use electronics and she combined that time with some PA: "He can watch TV, but there are certain rules... you have to run the 30 min, don't forget you have to exercise."

## 3.5.4. No family nearby

Participants indicated that in their native countries they had support from family members and believed that having such support would facilitate their participation in PA. Sophia stated that having family members close by would motivate her to promote PA for her family, saying, "I have more family in Puerto Rico...here we have no family...[my children] feel more stimulated, they have cousins, they have more friends who are close...here the American tends to be more enclosed each is in his own world." Participants had less contact with family and experienced cultural differences among American families, which made them feel isolated. For Amy, the fact that her family lived far away was a barrier to PA, along with her lack of trust in others: "Most of your family is not here, and two, the fact that you don't trust to leave your child with everyone." Since parents could not rely on close family or trust others to engage their child with ASD in PA, the responsibility of engaging their child in PA became their sole responsibility.

## 3.5.5. Finances

The cost of PA programs especially designed for children with ASD was another reason parents cited for not engaging their children in PA. Parents knew where to find resources for their children to be physically active, but they were not always able to afford the cost of the registration. Sophia and Elisa tried to enroll their children in swimming lessons, but cost was prohibitive. Paola placed her children in CrossFit but had to remove them because of financial reasons. Parents voiced that the resources they received were limited and they had to prioritize the use of this funding. Carla recognized that programs designed for children with ASD might be more expensive,

saying, "If you get charged \$300, for the child, they're going to charge you more...they're going to understand that [the child with a disability] needs a little more attention and that they're going to have to hire another person." Not only are financial resources strained, but participation in PA for children with ASD was sometimes more expensive than the options available for non-disabled children. Participants shared familial barriers that affected their PA participation, yet external barriers also affected PA opportunities.

## 3.6. Subtheme 2: shortage of appropriate year-round inclusive PA opportunities

Participants indicated a need for year-round inclusive programs in which they can engage in PA with their children and their entire families. Participants expanded that the lack of such programs aggravate their ability to be physically active. Parents shared several factors that are out of their control as a reason for their limited participation in PA. Some of these factors included: a) lack of accessible programs, b) lack of qualified professionals, and c) weather. Together with familial factors, these external factors reduced the ability to engage in PA as a family.

## 3.6.1. Lack of accessible programs

Parents believed that PA programs for children with ASD were scarce. Elisa explained that she found PA programs, yet would languish on a waiting list for over two years. According to Paola, when programs were available, she believed these programs were not suitable for her son: "There are programs, but often these programs do not accept children with disabilities." Parents indicated that if programs accepted children with disabilities, they would enroll their children in the program. Moreover, parents would like these programs to provide them with strategies they can implement at home with their children. Amy explained, "We haven't been able to find a place where they can welcome you to play and be trained. We've always found it as a barrier against children with autism." Amy did not like when programs were "one-time shots"; she believed that these programs were just for publicity, saying, "Oh, well, there go kids with special needs. They go and run... And that's it. And they take pictures and 'What a nice event!'... but there's no continuity, which is what I want." Amy expressed a preference for programs that welcome her child and where staff are well-qualified to work with children with ASD.

## 3.6.2. Lack of qualified professionals

Parents shared the belief that "experts", such as coaches and physical educators providing PA opportunities for their children, did not have the skills to work with children with ASD. Parents expressed the need for inclusive programs that are organized and supervised by qualified professionals. If such programs existed, they believed some of their specific barriers could be eliminated. According to Paola, if she paid for services, she expected her son would benefit from those services without her involvement, saying, "They're not going to tell you: 'We don't accept children with disabilities.' But they still ask you for help as a parent and for you to get involved, for the child to do exercises." Similar to Paola, Sophia believed that the physical education teachers at her son's school lacked the skills to make modifications for children with ASD: "When he goes to physical education activities, he's with regular groups. He doesn't get his accommodations according to his needs." Parents described several characteristics professionals should exbit. One of these was passion for the profession and the desire to help. Parents referenced their experiences with their children's schools, specifically in regards to physical education services. Parents indicated that they would like to have more communication with their child's physical education teacher, but that the PE teacher(s) did not attend the Individualized Education Program (IEP) meetings. Paola mentioned, "I've never seen the PE teacher... Actually, I've never thought about this." Furthermore, parents believed that the IEP team and the physical education teacher could connect families to PA programs in the community. Parents wanted these professionals to share information with them. In fact, Carla said that she would like these professionals to teach her what she needs to do: "They can teach you, 'Look, when the child does this, this is what it's recommended that you do, or you're going to modify the activity this way.' It's not really a science, but it takes time."

## 3.6.3. Weather

For those families who lived in areas with cold winters and snow, weather was another barrier. Elisa commented that because of the time changes that occurred during the winter the opportunity her family had to be active was minimal, "In the summer he has his bike...By the middle of winter, it starts getting darker." Similar to Elisa, other families commented that during the winter it was difficult to be active. Maria remarked, "There aren't many [opportunities] because the weather here is terrible...it is not the same as hiking in the winter...we've gone, and he's played in the snow. I come from a hot climate, for me this weather is not pleasant." Even though participants recognized they could not change the weather, and moving to a warmer location was not an option, many managed to be creative in findings ways to be physically active.

Paola shared some of her strategies to be active during the winter, "Taking them outside of the house and do a physical activity that they could put on their agenda. Because that's how they work. You put it on the agenda, and they follow their agenda." Because most parents were reluctant to go outside during the wintertime, Sandra indicated that she used YouTube to watch videos and searched for ideas of PA she could do with her child, "YouTube is a great resource... even the cold is not an obstacle for us." Sandra's family found alternatives to try to be physically active even during winter.

## 4. Discussion

Research dedicated to the study of the inclusion of children with ASD in PA reveals multiple challenges for these children and their families to be physically active (Barr & Shields, 2011). Despite a growing body of literature on this topic, little information is available

on the perspectives of Hispanic children with ASD and their parents. Moreover, little information is available about their motives and barriers to engaging in PA. The purpose of this study was two-fold: (a) to explore why Hispanic families with children with ASD seek out and participate in PA, and (b) to describe the barriers and supports needed by Hispanic families of children with ASD to improve PA participation. In this study, we uncovered some facilitators that may assist in the promotion of PA for this ethnic group. However, while we attempted to identify strategies to promote PA, it was evident that participants needed to share the obstacles they faced while attempting to engage in PA. The findings of this study gave a voice to a population that is typically absent in the current literature.

Previous research has shown that children with ASD tend to be less physically active than children without disabilities (Pan & Frey, 2005) and as they age, become even less active (Todd & Reid, 2006). Moreover, obese children with disabilities from diverse racial and ethnic groups face even greater challenges. A study by Rimmer, Yamaki, Davis, Wang, and Vogel (2011) showed that Black and Hispanic children with disabilities had a higher prevalence of obesity than other racial or ethnic groups and were less likely to be engaged in PA. Parents in the current study were aware that their children may be at risk for obesity and considered PA as a preventative strategy to challenge these predispositions. While it is encouraging that parents had knowledge about the benefits of PA, this is not enough.

Parents of children with ASD are typically integral social agents in children's PA choices and involvement (Nichols et al., 2019). The findings of this study are similar to previous litrature that report that parents and caregivers of children with ASD experienced challenges related to behavior management and inadequate support or training for PA (Ayvazoglu et al., 2015). Hispanic parents in the current study indicated that it was difficult for them to encourage their children to be physically active. Therefore, the need to focus specifically on ASD is important as participation patterns may vary considerably across differen types of disability.

One of the aims of this study was to have a better understanding of the experiences of Hispanic families of children with ASD when trying to involve their children in PA programs. A recurrent impediment mentioned by parents was the financial barriers they constantly encountered. Therefore, these families often cannot afford structured programs in which they can participate with their children. To alleviate the financial burden, parents articulated that they tried to participate in unstructured activities with their children. One of such activities was swimming. However, parents expressed that program fees prevented them from enrolling their children in swimming lessons. Swimming is one of the preferred activities among families of children with ASD (Alexander & Leather, 2013). This barrier is important to address for multiple reasons, primarily because drowning is the principle cause of death among children with ASD (Guan & Li, 2017). Therefore, providing options to decrease programmatic fees or even making swimming facilities affordable to these families is imperative so these children can have access to the facilities and develop proficiency in the water.

Weather conditions have also been frequently reported in the literature as a barrier to PA among families of children with ASD (Colombo-Dougovito & Block, 2019). Because of weather, families tend not to go outside and adopt sedentary activities. To overcome bad weather Obrusnikova and Miccinello (2012) highlighted the use of Wii Fit as a strategy to maximize PA. Parents in our study articulated the desire for online videos (e.g., Youtube) to look for games and activities that can be played at home. In both studies, technology was identified as crucial component of PA instruction and activity. Pardoxically, technology in this study was also viewed as a barrier to PA as it promoted sedentary behaviors. Further consideration on ways technology may promote or hinder PA for children with ASD is needed.

According to Schleien, Miller, Walton, and Pruett (2014), parents of children with ASD can find their role as facilitator particularly fatiguing. Yet, the support of peers, pets, and siblings has been mentioned as important factors to influence PA participation in after school programs (Obrusnikova & Miccinello, 2012). Therefore, parents of children with disabilities tend to rely on the support of their extended families and friends as a way to engage in social and sport activities (Twoy, Connolly, & Novak, 2007). In our study, however, parents reported that they were the only source of support and did not have the support of their extended family, who often were living in another country. As such, these families felt doubly marginalized. While they felt isolated because of the lack of programs, they felt further alone because they did not have family to rely on and engage in social and recreational activities. Therefore, culturally relevant PA interventions are needed to assist Hispanic parents in overcoming PA barriers. These interventions must be family-centered and must create an environment in which these families feel their needs, interest, and cultural backgrounds are included.

In several previous studies (Alexander & Leather, 2013; Nichols et al., 2019; Obrusnikova & Miccinello, 2012; Schleien et al., 2014) parents reported that availability of community programs or locations with developmentally appropriate and affordable PA opportunities (e.g., YMCA, Special Olympics, accessible playgrounds and parks) were a critical factor in their child's level of engagement and enjoyment of PA. However, with the exception of two parents, the rest of the participants in our study did not mention participation in any of these types of programs. It is possible that the families in our study are not aware of these programs or do not have access to them. Future research is needed to extend our knowledge regarding culturally responsive interventions for families with children with disabilities. Furthermore, these interventions need to teach families how to engage in PA and how to advocate for the inclusion and rights of their child (Suarez-Balcazar, Agudelo Orozco, Mate, & Garcia, 2017).

Other direct and significant factors that predict PA participation in children with disabilities include parents' perceived competence in their child's PA skills and abilities (Siebert, Hamm, & Yun, 2017). Parents expressed concern that they did not have the skills to teach PA to their children, as such, they want the professionals providing PA opportunities for their children to be qualified. This study also exposed parents' desire to have qualified professionals explain how they can modify activities for their child, which may as a result influence parents' perceived competence in their child's PA skills. PA programs and interventions that provide training for parents of children with ASD regarding PA engagment and participation are highly needed. These programs may benefit from providing support and guidance for parents about how to provide increased parental support and address the beliefs and attitudes towards their child's physical ability level. Moreover, these programs can educate parents on strategies to overcome barriers to PA. One such example is the Fit Families Program (Davis et al., 2017). The Fit Families Program (FFP) is a PA program designed to maximize PA opportunities for children with autism and their families (Davis et al., 2017). This initial program consisted of four one-day workshops focusing on the

areas of: 1) Sensory Integration, 2) Communication, 3) Aquatics, and 4) PA and Sports. Each workshop had three main components: 1) Individual workshop for parents, 2) Physical activities and games for the children, and 3) Combined interaction between parents and their children. This interaction provided an opportunity for parents to practice the skills they learned with their children. This also provided an opportunity for the children to show their parents the skills they acquired during the different activities. The Fit Families Program is one example of a facilitated PA program for children with ASD and their families to build skills and confidence in PA.

## 5. Limitations of the study

This study has some limitations. This study was limited to the experiences of Hispanic parents of children with ASD from five different states mostly in the Eastern part of the U.S (Georgia, Florida, New York, Massachusetts and Texas), and more research is needed before generalizing results to other regions. Furthermore, the participant's neighborhood environment was not assessed, therefore, it is not clear if participant's neighborhoods promoted Hispanic cultures and community-building, which may affect participant's perception of available familial support. Although, this qualitative study does not have a nationwide sample, the study design is a foundation for future larger scale studies.

While multiple parents or caregivers of the children with ASD were invited to interview, we were unable to engage more than one parent of each child during the interview process. Therefore, having only one parent participating limited the amount of information captured and provided only one perspective. Further, since all participants identified as mothers, this may have increased the potential gender bias of the responses. The similarities and differences among how mothers and fathers view PA experiences with their child would be interesting, especially given the different gender roles parents may play in sport and PA participation for their children and themselves. While multiple parents or caregivers of children with ASD were invited to participate in the interviews, only mothers responded. This limited the study results because it provided only one caregiver perspective for each child may have increased the potential gender bias of the responses. It would have been interesting to examine the perspectives of fathers, single-gender parental households, or grandparents raising children, for example. Also, this study did not include any families with girls with ASD. Therefore, we cannot extend our analysis to similarities and differences in the experiences of male or female children. Further, the current study included only a narrow age range. Future studies can expand the age range of the children and potentially identify additional differences.

Additionally, examining the influence of cultural norms on PA participation could further reveal how ethnicity does or does not impact PA participation for children with ASD. This is especially important considering Hispanic is a broadly defined ethnicity that intersects with race and includes various cultural norms that differ among regions and countries. For example, a Hispanic family who has recently immigrated to the United States has different experience and perception of cultural norms than a third-generation Hispanic family or a family from Puerto Rico. Therefore, further research interviewing several families from a variety of regions and countries could add to the current study.

## 6. Conclusion

Research exploring the perspectives of parents of children with ASD are limited. However, a general understanding of parents' experiences when trying to introduce their children with ASD to PA were exposed in this study. While it was our intention to identify appropriate strategies to promote PA among this underserved population, the results shed light into the barriers these families experienced. The barriers identified in this study can provide general information about what PA professionals need to do to enhance PA participation among Hispanic families of children with ASD.

While voicing a great value for PA for themselves and their children, often families' PA participation was curtailed due to lack of time, finances, and inclusive programming. As such, they opted to participate in unstructured PA or in some cases they preferred to remove their children from PA programs. Parents also called for the development of inclusive programs led by qualified professionals. These parents wanted information and ideas from professionals on how to engage their children in PA. In some cases, parents provided strategies they implemented to encourage PA for their children such as making PA a priority and scheduling in in their calendar. Furthermore, given the fact that children with ASD are drawn to technology, parents used technology as a reward system for their children. Future research should expand upon these facilitators. Most important, intervention research is needed to eliminate some of the barriers exposed in this study by Hispanic parents of children with ASD.

## CRediT authorship contribution statement

Luis Columna: Visualization, Conceptualization, Investigation, Methodology, Writing - review & editing. Genesis Felizola: Conceptualization, Investigation, Methodology, Writing - review & editing. Laura Prieto: Conceptualization, Investigation, Methodology, Writing - review & editing. Beth Myers: Conceptualization, Investigation, Writing - review & editing. Denzil Streete: Methodology, Writing - review & editing. Anita Lightburn: Conceptualization, Methodology, Writing - review & editing.

## **Declaration of Competing Interest**

The authors report no declarations of interest.

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