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Identifying and Understanding Anxiety in Youth with ASD: Parent and School Provider Perspectives on Anxiety within Public School Settings

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ABSTRACT

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is characterized by difficulties with social-communication and the presence of restricted and repetitive patterns of interest. It is well documented that children with ASD often experience co-occurring psychiatric difficulties, including anxiety. In fact, it is estimated that between 40 and 79% of children and adolescents with ASD experience at least one anxiety disorder. This range in prevalence is likely due to differences in study sample size and recruitment practices (e.g., community versus clinical samples), in the use of screening measures with reduced sensitivity to detect anxiety in ASD, in sample characteristics (e.g., child's IQ, language skills), as well as differences in the presentation of anxiety in ASD. Anxiety disorders in youth with ASD can significantly interfere with functioning across school, home, and community settings, and anxiety related difficulties are thought to exacerbate core ASD symptoms, including increased avoidance and ritualistic/restricted behaviors. Within school settings specifically, anxiety may negatively impact class attendance and engagement, academic achievement, and peer relationships. Thus, learning more about anxiety difficulties at school can inform the development of school-based mental health interventions for students with ASD. Identifying anxiety within school settings can also facilitate appropriate selection of students with ASD experiencing anxiety, thereby fostering the academic and mental health functioning in these students.

Identification and access to mental health services for students with ASD

Even though children with ASD are at high risk for anxiety difficulties, they are less likely to receive appropriate intervention services, including mental health services to address co-occurring anxiety symptoms (Montes et al., 2009). It is estimated that approximately 20% of youth with ASD are able to access necessary mental health services, including anxiety-related services (Bromley et al., 2004). One reason for limited access may be due to a failure to recognize or identify the anxious youth with ASD who need services (Kerns & Kendall, 2012).

Several factors may hinder the timely and accurate identification of these symptoms (and thus limit access to anxiety-related services). For example, youth with ASD may have difficulty reporting (or even recognizing) their own anxiety symptoms, leading clinicians to identify these conditions based

primarily on parent report and/or observable behaviors. Additionally, anxiety-related behaviors may manifest in non-traditional ways for youth with ASD (Kerns et al., 2019, 2017), exacerbating difficulties with accurate identification. That is, some youth with ASD display distinct fears or worries, (e.g., fear of men with beards; worry regarding lack of access to special interests), which may be attributed to core deficits of ASD, but could also be attributed to co-occurring anxiety conditions (Kerns et al., 2019). Finally, diagnostic overshadowing can occur; that is, anxiety symptoms may be considered to be part of ASD, rather than recognized as a separate set of co-occurring symptoms (Reiss et al., 1982). For example, the presence of social avoidance could be ascribed to core ASD symptoms without further exploration as to whether a diagnosis of Social Anxiety Disorder could also be present (Kerns et al., 2015). When

diagnostic overshadowing occurs, anxiety symptoms are minimized and/or missed altogether, resulting in missed opportunities to receive intervention for these symptoms.

The challenges of identifying anxiety symptoms may be increased in youth with ASD from underserved racial and ethnic minority backgrounds (Zachor et al., 2011). In one study, providers working with diverse youth with ASD missed the presence of internalizing symptoms due to potential bias toward identifying externalizing disorders in these youth (Chavira et al., 2004). This misinterpretation of anxiety symptoms in diverse youth could, in turn, explain why some children from low SES and minority backgrounds are less likely than their peers to obtain specialty care and/or much needed mental health services (Broder-Fingert et al., 2013; Magaña et al., 2013; Zeleke et al., 2019). However, there is still a limited understanding of whether anxiety may present or be interpreted differently for these youth.

Caregivers and school providers are well positioned to provide much needed information regarding the manifestation of anxiety in students with ASD, as well as to highlight the potential gaps/barriers in the identification of anxiety symptoms. In one study, parents and teachers reported increased behavior and emotional problems in youth with ASD using rating scales (Salomone et al., 2014). This study also reported that only a limited number of children were receiving mental health services. Understanding their perspective on how children with ASD and anxiety are identified may help to improve identification efforts within schools, which, in turn, could lead to increased access to anxiety-related services in an important and inclusive system of care (Davis et al., 2006; Tolan & Dodge, 2005). It is estimated that close to half of students with ASD who have participated in mental health services have received those services at school (Narendorf et al., 2011).

In summary, previous research indicates that children with ASD experience high rates of co-occurring anxiety; however, only a small percentage of children with ASD access anxiety-related services in the community. Children with ASD from traditionally underserved (e.g., African-American; Latinx, low SES) communities may be even less able to access mental health services. One notable

barrier to accessing anxiety services may be that anxiety symptoms are difficult to accurately identify in youth with ASD and may be even more difficult to identify in diverse youth with ASD. Specifically, the biases toward identifying externalizing behaviors in diverse neurotypical youth (rather than internalizing symptoms) may also be at play for diverse youth with ASD, as reported in a non-ASD sample (Last & Perrin, 1993).

Current study

The primary aim of the current study was to understand how students with ASD are identified with anxiety in public school settings, with a particular focus on students from traditionally underserved communities. The current study was part of a larger qualitative research project focused on the adaptation of an evidence-based anxiety intervention for youth with ASD (e.g., Facing Your Fears: Group Therapy for Managing Anxiety in Children and Adolescents with Autism Spectrum Disorder (FYF); Reaven et al., 2011) for students with ASD and anxiety in urban schools (Reaven, Reyes, Pickard, Tanda, & Morris, 2019). The following questions/topics were addressed in the present study:

- (1) *How does anxiety typically manifest within school settings for students with ASD?*
- (2) *What is the referral process for children with ASD experiencing anxiety difficulties?*
- (3) *Do children with ASD and anxiety symptoms tend to be missed and/or misdiagnosed, and if so, what are the possible reasons that this may occur?*

Methods

Study design, procedures, and participants

To address the aims of this study and the specific research questions stated above, parent and provider stakeholders were recruited to participate in focus groups using qualitative content analysis methodology (Hsieh & Shannon, 2005). More extensive details regarding the specific procedures are documented in this larger study (Reaven et al., 2011, 2019) and, therefore, are summarized here briefly.

A total of 23 parents and 17 school providers across three public school districts in Colorado were recruited as part of this study. Demographic information for participants is documented in Table 1. Parents and school providers were invited to participate in two 90-minute focus-groups. All parents had a child with a diagnosis of autism spectrum disorder (ASD). Participating school providers were interdisciplinary professionals (e.g., speech/language pathologists, special/general educators, occupational therapists, administrators, etc.) and were currently working in schools/classrooms educating students with ASD. This study was completed in compliance with the (2011) ([2011]) and with the Institutional Review Boards of each school district.

Data collection

All focus groups occurred between October 2017 and April 2018 within a school in one of the three school districts or at the University of Colorado (2011). The purpose of the first focus group was to solicit information regarding the identification of anxiety in diverse public school settings. The second focus group was convened with the same participants to “member check,” or present preliminary findings

from the first focus group to confirm and further refine the data interpretation (Creswell, 1998).

All focus groups were moderated by one to two doctoral level study team members, one of whom had extensive experience with qualitative methods of data collection and analysis. Prior to the focus groups, parents and school providers completed a demographic survey that collected information including age, gender, race/ethnicity and educational attainment. Also, school providers and parents provided information about their professional roles, and the age of their child with ASD, respectively. A semi-structured interview guide was created that inquired about participants’ perspectives regarding the manifestation, identification, and screening of anxiety in students with ASD within school settings, as well as whether students with ASD might get missed or misdiagnosed, and strategies or approaches (if any) to enhance anxiety identification in students with ASD, especially among those from traditionally underserved backgrounds.

Data analysis

Data analytic procedures mirrored those reported in (Reaven et al., 2011, 2019). Briefly, all focus

Table 1. Sample demographics.

Professionals (n = 17)		Parents (n = 23)	
Age	43.47 years old (range: 31–70 years)	42.62 years old (range: 31–52 years)	
Gender	Male: n = 3 (13.04%) Female: n = 20 (87%)	Male: n = 3 (13.04%) Female: n = 20 (87%)	
Ethnicity	Non-Latino: n = 14 (82.35%) Latino: n = 1 (5.88%) Did not report: n = 2 (11.76%)	Non-Latino: n = 18 (78.2%) Latino: n = 3 (13.04%) Did not report: n = 2 (8.7%)	
Race	Non-Latino White: n = 14 (82.35%) American Indian/Alaska Native: n = 1 (5.88%) African American/Black: n = 1 (5.88%) Did not report: n = 1 (5.88%)	Non-Latino White: n = 13 (56.52%) Asian: n = 2 (8.7%) African American/Black: n = 3 (13.04%) Multiracial: n = 2 (8.7%) Other: n = 1 (4.35%) Did not report: n = 2 (8.7%)	
Professional Roles	General Education Teacher: n = 1 (5.88%) Special Education Teacher: n = 4 (23.53%) Social Workers: n = 1 (5.88%) School Psychologist: n = 5 (29.41%) Occupational Therapist: n = 1 (5.88%) Speech Language Pathologist: n = 1 (5.88%) Administrator: n = 2 (11.76%) Other: n = 2 (11.76%)		
Caregiver Education			High School: n = 2 (8.7%) High School Diploma: n = 3 (13.04%) Associates: n = 3 (13.04%) College: n = 10 (43.48%) Master: n = 5 (21.74%) PreK-2nd grade: n = 5 (21.75%) 3rd grade – 5th grade: n = 6 (26.1%) Middle school: n = 9 (39.1%) High School: n = 1 (4.35%) Post High School: n = 2 (8.7%)
Child's Grade			

groups were audio recorded and transcribed verbatim, with identifying information removed. Transcripts from the first and second round of focus groups were analyzed together by a multidisciplinary research team. Team members initially independently reviewed a subset of the transcripts to inductively identify open codes (i.e., a simple code that represents the verbatim meaning of a segment of text). The team then met to reconcile and condense their coded transcripts and codebooks to identify an initial consolidated codebook. The team then independently applied this codebook to another set of transcripts, before coming back together to reconcile and adapt the codebook as needed. This process was repeated twice until no new codes were added and team members were well versed in codebook definitions. Team members then independently applied the final codebook to the remaining transcripts. Each transcript was coded by two team members, who first coded the transcript independently and then met to compare their coded transcripts. All discrepancies were reconciled through consensus. If consensus was not able to be reached, any remaining discrepancies were brought to the full team to be decided. The final coded transcripts were then entered into Atlas.ti for data management and to support interpretation. The team analyzed the coded data across and within different participant groups to identify primary and secondary themes that directly mapped onto the study aims (i.e., those related to the identification of anxiety within diverse students with ASD in school settings).

Results

Focus group participants reported similar views and perspectives across school districts and across groups of parents and school providers; therefore, data are reported together. The following themes emerged from the parent and school provider focus groups: 1) *Anxious behaviors in youth with ASD at school*; 2) *Triggers of anxiety in school settings*; 3) *Process of identifying/assessing anxiety in schools*; 4) *Children whose anxiety is missed and why it is missed*; and 5) *Strategies to improve anxiety identification at school* (See [Table 2](#)).

Theme 1: anxious behaviors in youth with ASD at school

Parents and providers described that anxiety manifests in a variety of behaviors for youth with ASD and anxiety at school. As one parent shared, “*Every autistic kid is different. Anxiety for every autistic kid is different.*” Specific behaviors most frequently endorsed by parents and providers included avoidance, externalizing behaviors, an exacerbation of core ASD symptomatology (i.e., repetitive behaviors), and physical complaints.

Avoidance

Avoidance was one of the most frequently cited anxious behaviors by both parents and school providers. For some youth, avoidance was viewed as manifesting prior to attending school (i.e., school refusal) in addition to work avoidance during school. One school provider stated, “*I would say*

Table 2. Themes derived from parents’ and school providers’ interviews.

	Primary Themes	Secondary Themes
Theme 1	Anxious behaviors in youth with ASD	-Avoidance -Externalizing behavior -ASD symptoms -Physical complaints
Theme 2	Triggers of anxiety	-Social situations -Political climate for students from diverse background -School setting/activities (e.g., fire alarms, assemblies)
Theme 3	Identifying and assessing anxiety	-Staff: classroom teachers -Measures to assess anxiety: observation, anxiety rating scales, and functional behavior assessments
Theme 4	Children whose anxiety is missed and why	-Knowledge about anxiety by school providers -Misinterpretation of anxiety symptoms -Parent factors (e.g., knowledge about anxiety, stigma about mental health)
Theme 5	Strategies to identify anxiety at school	-Training for teachers to increase knowledge about anxiety (e.g., avoidance, oppositionality, and other externalizing behaviors could have an underlying function of anxiety; anxiety might also manifest in physical symptoms as well as an increase in repetitive behavior) -Increasing parent trust (e.g., developing a positive relationship with parents) -Decreasing mental health stigma (e.g., show parents objective data)

‘work avoidance,’ which then could manifest in lots of different ways from just sitting there with the head down or not doing the work or talking out or getting distracted or avoidant behavior.”

Externalizing behavior

Parents and school providers often indicated that youth who are anxious sometimes have physical outbursts, anger, or challenging behavior within school settings, and that these behaviors can be quite difficult to distinguish from anxiety. One parent described, *“I still get so amazed by how it just is all over, like I’m going to punch and kick anyone, so it gets aggressive. Just super unreasonable.”* Within school settings, anxious students with ASD were also described as being more likely to have conflict with peers. One hypothesis provided was that this conflict or aggression around peers might permit students to leave the situation.

Causing conflicts with peers I think we see sometimes. I think it appears that their hope is that they’ll then be removed, that ‘I might cause enough of a distraction with my peers or if I threaten someone or if I physically move a chair, then I will be removed.’

Core ASD symptomatology

In addition to avoidance and externalizing behaviors, many school providers described that they observe students’ core ASD symptoms tend to increase or are more evident when they are anxious. For some students this was viewed as an increase in repetitive behaviors, such as clapping, pacing, and rubbing their hands together. In addition to repetitive behaviors, one school provider reported, *“I’ll see a lot more, again especially with our ASD kiddos, more scripting and things like that, too, that will then indicate to me that they are anxious.”*

Physical complaints

Finally, school providers and parents also indicated that students with ASD frequently report physical complaints that may signal anxiety rather than true illness. These complaints were described as often resulting in a trip to the nurse’s office and missed educational time. *“So, the somatic complaints would be another symptom. ‘I have a headache. I have a stomachache. Call the nurse. Can I go to the nurse?’ Those kinds of things we see a lot.”* For

other students, parents stated that physical complaints rooted in anxiety make it extremely difficult to get them to leave for school in the morning.

Theme 2: triggers of anxiety in school settings

Participating parents and school providers stated that a variety of situations can trigger anxiety within school settings given the many demands that are placed on students. A majority of participants described that loud noises (e.g., fire alarms, assemblies, announcements over the intercom, etc.), and changes in the school routine (e.g., having a substitute teacher) cause anxiety for students with ASD. They reported that these situations often cause students to become overwhelmed, tantrum, or “shut down.”

Social situations

Other parents and school providers also emphasized that social situations, including the need to give a class presentation, work on a group project, and/or enter a new peer group as being very challenging for some students with ASD. One parent stated, *“He avoids talking to people and playing with other kids. He goes into a room to be alone, he would shut down and hide rather than be around them.”* Participants described that one aspect of what makes social situations challenging for students with ASD is the unpredictable and, sometimes, rule breaking behavior of peers:

If a teacher doesn’t respond appropriately [to] the way he feels as if they should respond, he becomes angry and he does not wanna talk to them. It’s like, ‘but you guys know the rules already. How come you’re not following them? You’re the teacher. You’re supposed to enforce [...] ‘now I don’t wanna talk.’

The role of political climate on anxiety for diverse students

In addition to the common anxiety triggers outlined above, some parents and school providers described that the current political climate played a role in increased anxiety and that this is particularly true for students of color. One participant stated, *“The cultural component and having to deal with racism is really horrendous. There is an underlying anxiety there all the time for many kids.”* School providers also believed that anxiety for

Latinx students appeared rooted in recent changes in immigration policy. One school provider said:

The political climate is also a current huge stressor for the students that we're wanting to work with. I've had multiple students come talk to me. Again, that's where it crosses that line of anxiety. We talk about it's an irrational fear. These aren't irrational. It's like, 'My parents might be deported.' That's a real thing.

Theme 3: process of identifying and assessing anxiety in schools

Participants were asked about how students with ASD are formally identified as having anxiety within school settings. School providers and parents reported that the process of identifying anxiety symptoms in students varies by school.

Staff identifying anxiety

In general, school providers indicated that classroom teachers often start the process of initiating support for an anxious student. One provider described:

It's usually the classroom teacher who will start the process, kind of make the referral to the principal where we'll put some stuff in place and try some things before we do a formal evaluation." Another school staff member stated, "We have a student intervention team, but then we also have over the past few years created a team which is called Behaviors Interfering with Learning. So, that's kind of where we get those kids which maybe it is anxiety related.

Measures to assess anxiety

Overall, a variety of standardized and unstandardized tools were reported as being used to help identify anxiety. Variability in measurement was significant across schools and provider roles, with staff reporting that they use some combination of observation, anxiety rating scales, and functional behavior assessments as tools to quantify student anxiety. Staff also reported that there is some flexibility in the way that anxiety and other emotional difficulties are measured and that:

A lot of it is dictated by what the district wants us to use. So, if the child's difficulty and stress seem to me to be around executive function, I might go with the BRIEF. If I really want to tease apart anxiety from naughty

behavior, then I might use something else. And then I also would look at large environments versus small environments. So, if the student is in a smaller intervention group, it would be valuable to give the measure to the teacher in addition to the classroom teacher.

Theme 4: why anxiety is missed in children with ASD

Both parents and school providers indicated that a subsample of students have anxiety symptoms that are undetected or missed. They reported that a number of factors might contribute to not detecting anxious symptoms in these youth.

Lack of knowledge and misinterpretation of anxiety symptoms

It was perceived that school provider factors may contribute to missing anxiety in youth with ASD. For instance, participants described that school providers' knowledge and understanding of anxiety is critical to identify anxiety symptoms. Both school providers and parents described that not all school providers are trained in identifying anxiety and that this may contribute to the misinterpretation of anxiety symptoms as behavioral problems. For example, school providers may view anxiety difficulties as problem behaviors, especially in youth from low SES or minority backgrounds. Additionally, parents reported that symptoms of ASD might overshadow anxiety and that many school providers do not have experience in teasing apart anxiety from the core characteristics of ASD. A parent noted:

You'd have to train the teachers to know what to look for because you could have that child who is quiet You're gonna overlook those kids, 'cause you don't think there's a problem, but they could be suffering from anxiety, but you're gonna get the ones who are acting out . . . When he got evaluated, we looked at oppositional defiance disorder, and it turned out no, it was due to autism. The rigid/inflexible thinking and anxiety is what was causing what appeared to be oppositional defiance.

Mental health stigma

School providers indicated that there is stigma around mental health difficulties in general and reported that they take culture into consideration when making recommendations to families. They described that some cultures may not welcome

extra support at home or at school for their children and that this is especially true for services aimed at supporting mental health. One parent stated:

I think that people often think mental health is like negative. There's a lot of negative connotation that goes around it. And it's – you know when you already deal with a child that already has a – is non neuro-typical in whatever fashion, they don't deal with life as easily as neuro-typical people.

Other school providers shared that, when they discuss with parents that their child is experiencing anxiety at school, some parents express that they do not see these difficulties at home or in the community. One participant shared that a parent may say:

You guys must be doing something, we don't see this at home so maybe it is the teacher or the administrator or the other kids or the classroom, so it is not my child's problems, it is someone else's problem.

School providers indicated that presenting information as results, numbers, or outcomes could also help minimize stigma. For example, they show parents information or data can be helpful because it appears more impartial (e.g., they might see numbers as more objective). A parent shared:

I think outcome is very important. If they see positive outcome, I mean whether you agree to it or not, if you have an outcome, I mean it's helping them at home. They don't have to always, you know go against, you know.

Other parent factors

A majority of school providers and some parents reported that *parent factors*, such as parents' own understanding and knowledge of mental health difficulties can be a barrier to identifying students with ASD who are anxious. For example, participants shared that parents might not know that their child is experiencing anxiety. School providers also believed that some parents do not know how to advocate for their children at school who have ASD and may also have anxiety (e.g., requesting for qualifying assessments to determine if their child can receive services for anxiety). One parent, who was knowledgeable about school related policies, had comments about parents who do not have that knowledge:

... We know all the systems. We know all of the things that – the right people to talk to about the right things in the right ways. There's a lot of folks that don't, so those kids whose parents may not know how systems work ... without a door, they won't know how to go in it.

English language fluency was also reported as an important factor impacting anxiety detection in youth with ASD. Participants indicated that, for families who are not fluent in English, interpreters are needed to support parents in communicating with school teams. Importantly, due to immigration policies, participants described that these, "parents don't feel that they're in safe places for them or family members," making advocating for their child's emotional needs even more difficult:

They have lack of experience within the school system, as a teacher, so I know [for] some cultures –the school district, it's God, and it's gospel, and they don't question it – 'Okay. The school knows more than I do, so I'm gonna go by what the school's saying ...' So sometimes that is a cultural barrier that they'll just say, 'Okay. The school's doing – the school tells me what to do. Okay ...' It's just that's their culture not to question.

Strategies to identify anxiety at school

Training for teachers

In general, school providers suggested that providing trainings and increasing teachers' knowledge about mental health would increase their confidence in identifying and managing anxiety symptoms. Also, training school providers with interventions targeting anxiety in schools may be useful because school is often, "*The only consistent place that the child can get that [an anxiety intervention].*" School providers believe that training in schools would increase access to evidence-based intervention for underserved youth, who they might not otherwise serve. A school provider added:

So it's training teachers to dig a little deeper when they look at behavior, both outward-causing problems and inward quiet. Just because they're well behaved doesn't mean they're not suffering from anxiety.

Increasing parent trust and decreasing stigma

Participants shared that it is essential to develop trust with the families by engaging them in conversations tied to mental health and anxiety to decrease stigma

and support access to anxiety interventions. For example, families were described as being more receptive to discussing their child's mental health needs with people whom they know and trust. Additionally, school providers recommended presenting mental health information in a way that is not as stigmatizing. For example, parents and school providers suggested presenting visual data because it appears more impartial (e.g., they might see numbers as more objective). It was also suggested that describing a child's anxiety symptoms in terms of how it may interfere with child's success may also decrease stigma. A school provider suggested the following:

Independence as part of that, what the goal is, to build independence in your child, to build success. It is important to being open to what other cultures value and if there is something that they are OK with, or just being respectful of their values.

Discussion

The goal of this study was to obtain parents' and school providers' perspectives on how anxiety symptoms manifest in children with ASD within school settings. Specifically, participants were asked about the presentation of anxiety within school settings, the screening and referral process for identifying anxiety, barriers to identifying anxiety symptoms in diverse students with ASD, and why some children with ASD and anxiety are not identified. Several themes emerged from the focus group participants: 1) children with ASD tend to show a wide range of anxious behaviors at school; 2) there are a number of events/situations that can trigger anxious behaviors; 3) the process of identifying/assessing anxiety can vary widely from school to school; and 4) several factors may contribute to why some children with ASD are not identified as having anxiety. Finally, a number of recommendations were suggested by the focus group participants to improve identification of anxiety within school settings.

Consistent with previous research, these findings indicate that youth with ASD tend to show both similar and unique anxiety difficulties as compared to neurotypical peers (Kerns et al., 2019). Parents and school providers stated that youth with ASD often display anxiety symptoms at school, and frequently in the form of avoidance, externalizing behaviors,

and physical complaints. Different from their peers, anxiety difficulties might increase core ASD symptomatology (i.e., repetitive behaviors, worry about changes in routines). This is important because a naïve observer may miss the presence of anxiety symptoms (or other mental health symptoms), and potentially falsely attribute symptoms and behaviors in their entirety to the core symptoms of ASD.

Regarding triggers for anxiety in school settings, parents and school providers indicated that youth with ASD and anxiety can often be triggered by school-specific environments or situations, such as loud events, changes in school routines, and social situations/academic groups. Diagnostically, these symptoms may be suggestive of specific phobias (e.g., fire alarms, idiosyncratic phobias of noises), fear of change (e.g., changes in routines), and social anxiety (e.g., school assembly). That is, different from their peers, youth with ASD may experience increased difficulties associated with social anxiety and specific phobias (Kerns et al., 2017). Importantly, anxiety symptoms likely interfere with these students' ability to fully engage and participate in a variety of activities across the school day (Adams et al., 2018). Notably, school providers seemed to believe that the current political climate (e.g., increased negative views toward immigrants) appeared to play a role in increasing anxiety symptoms in Latinx children.

With respect to identifying anxiety in schools, it was reported that the process varies widely from school to school. Often, general education teachers were identified as being at the forefront when identifying children with ASD and anxiety. Once a child is identified or referred due to the presence of interfering anxiety symptoms, school providers commonly use a multimodal approach to the assessment of anxiety related difficulties, including parent/teacher rating scales/questionnaires (standardized measures), functional behavior assessments, and informal classroom observations.

Although many children with ASD and anxiety are identified, referred, and assessed as having anxiety difficulties within school settings, parents and school providers expressed that some children with ASD and co-occurring anxiety symptoms are missed. Reportedly, the reasons for this lack of identification is multifactorial, and parent and teacher factors were described as playing a role. For

example, parents and school providers believed that lack of school providers' knowledge about anxiety or misinterpretation of symptoms likely interfere in the identification of anxiety symptoms in ASD. The misinterpretation of symptoms is also likely to occur particularly for children from diverse backgrounds. These findings parallel previous research that indicates disparities in identifying ASD in minority children (Pettygrove et al., 2013) and perhaps biases in identifying anxiety in diverse neurotypical youth. Although this was not mentioned by school providers or parents, anxiety symptoms may also be missed because the screening measures typically used within school settings have not been validated with children with ASD (e.g., Rodgers et al., 2016).

Moreover, parent factors, such as concerns regarding mental health stigma, knowledge about anxiety, advocacy skills, and English language proficiency are also likely to delay the identification of symptoms and access to services in youth with ASD. In general, similar barriers may also interfere with receiving mental health service or specialized care in families from diverse backgrounds (Magaña et al., 2013; Zeleke et al., 2019; Zuckerman et al., 2017). The findings of this study extend this need to that specifically of mental health and anxiety and appears particularly important in light of its significant negative impact on student engagement and functioning at school.

Positively, participants suggested several strategies to improve anxiety identification at school. Given that teachers appear to play a significant role when identifying anxiety, it was recommended that they participate in mental health training to increase their knowledge about the presentation and triggers of anxiety in youth with ASD. These trainings could, in turn, increase teachers' self-efficacy and confidence in dealing with anxiety difficulties in their students with ASD. The need for increased training for teachers regarding ASD, as well as evidence-based interventions for ASD have been reported in previous research (Sanz-Cervera et al., 2017; Stahmer et al., 2015; Wood et al., 2015). However, more research is needed to determine what teachers know, and how they learn about anxiety to develop and implement appropriate mental health trainings (Adams et al., 2018; Headley, & Campbell, 2013; Walter, Gouze, & Lim, 2006).

In addition to teacher trainings, it was suggested that school providers work to develop positive relationships with parents and gain their trust, as parents may be more likely to discuss their child's need for mental health services with a school provider they knew well. Similar strategies have been reported to increase collaborative relationships between parents and teachers (Voltz, 1994). Developing positive relationships between parents and school providers may also increase school provider knowledge of children's mental health needs (Iruka et al., 2011), and may make it more likely that parents share their perspective and views about mental health and services. It was also proposed to decrease parental stigma around mental health by increasing parent's knowledge about the relationship between mental health services, positive outcomes, and child's academic success.

Limitations and recommendations

Some limitations of this study should be noted. Results from this study cannot be generalized to all children with ASD, as only English-speaking families from urban school districts were included. Additionally, despite having a diverse sample of participants, the perspective of the families and providers who volunteered might be different from other families (e.g., families who participated might be more knowledgeable about their child's anxiety difficulties). Finally, students with ASD did not share their own views about their experiences with anxiety.

It is recommended that school providers consider using screening measures, such as the Parent-Rated Anxiety Scale for Youth with Autism Spectrum Disorder (PRAS-ASD, Scahill et al., 2019) and the Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD, Rodgers et al., 2016), that have been normed for students with ASD and anxiety, to better capture anxiety related difficulties in ASD. It may also be helpful to provide regular training in school settings to interdisciplinary providers (not just teachers), as well as parents on mental health and ASD. An effort could be made to offer parent groups, especially families from diverse communities who may have less knowledge or experience increased stigma related to mental health. With regard to knowledge about mental health, it would be beneficial to increase efforts in graduate programs for young

professionals across disciplines to have increased awareness about mental health and ASD. Due to increase use of video conferencing and distant learning because of COVID-19, telehealth could also be a tool to provide information to school providers and parents about mental health (Hepburn et al., 2016). Finally, interventions designed to manage anxiety in youth with ASD within school settings, such as Facing Your Fears, and Exploring Feelings, appear to be efficacious in decreasing anxiety symptoms in ASD and could also be considered within school settings (Clarke et al., 2017; Drmic et al., 2017; Luxford et al., 2017; Sofronoff et al., 2005).

To summarize, this study is novel in that it provides insight into the anxiety difficulties that youth with ASD experience at school beyond simply reporting the prevalence and severity of anxiety symptoms within school settings (e.g., Salomone et al., 2014). Different from previous research, the qualitative methods used within this study allowed for a much richer description of the process by which anxiety is identified and supported within diverse students with ASD (Syriopoulou-Delli et al., 2019). This study also demonstrated that several parent and teacher factors may interfere with the identification of anxiety in ASD. Finally, recommendations on how to improve the identification of anxious children with ASD and interventions to manage anxiety were also proposed. Results from this study highlight the need for research aimed at increasing both the identification of anxiety symptoms within school settings and access to evidence-based interventions for children with ASD (Fazel et al., 2014; Luxford et al., 2017). This is particularly important in light of the significant and negative impact of anxiety on student engagement within schools. It is likely that culturally responsive interventions that are designed to increase knowledge about mental health, to simplify referral processes, and to decrease mental health stigma, are likely to increase equitable access to these services within an important system of care (Gordillo et al., 2020).

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References

- Adams, D., Simpson, K., & Keen, D. (2018). School-related anxiety symptomatology in a community sample of primary school aged children on the autism spectrum. *Journal of School Psychology, 70*, 64–73. <https://doi.org/10.1016/j.jsp.2018.07.003>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Author.
- Broder-Fingert, S., Shui, A., Pulcini, C. D., Kurowski, D., & Perrin, J. M. (2013). Racial and ethnic differences in subspecialty service use by children with autism. *Pediatrics, 132* (1), 94–100.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*(4), 409–423. <https://doi.org/10.1177/1362361304047224>
- Chavira, D. A., Stein, M. B., Bailey, K., & Stein, M. T. (2004). Child anxiety in primary care: Prevalent but untreated. *Depression and Anxiety, 20*(4), 155–164. <https://doi.org/10.1002/da.20039>
- Clarke, C., Hill, V., & Charman, T. (2017). School based cognitive behavioural therapy targeting anxiety in children with autistic spectrum disorder: A quasi-experimental randomised controlled trial incorporating a mixed methods approach. *Journal of Autism and Developmental Disorders, 47*(12), 3883–3895. <https://doi.org/10.1007/s10803-016-2801-x>
- Creswell, J. W. (1998). *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, CA: Sage.
- Davis, A. S., Kruczek, T., & McIntosh, D. E. (2006). Understanding and treating psychopathology in schools: Introduction to the special issue. *Psychology in the Schools, 43*(4), 413–417. <https://doi.org/10.1002/pits.20155>
- Davis, T. E., III, Moree, B. N., Dempsey, T., Reuther, E. T., Fodstad, J. C., Hess, J. A., Jenkins, W. S., & Matson, J. L. (2011). The relationship between autism spectrum disorders and anxiety: The moderating effect of communication. *Research in Autism Spectrum Disorders, 5*(1), 324–329. <https://doi.org/10.1016/j.rasd.2010.04.015>
- Drmic, I. E., Aljunied, M., & Reaven, J. (2017). Feasibility, acceptability and preliminary treatment outcomes in a school-based CBT intervention program for adolescents

- with ASD and anxiety in Singapore. *Journal of Autism and Developmental Disorders*, 47(12), 3909–3929. <https://doi.org/10.1007/s10803-016-3007-y>
- Fazel, M., Hoagwood, K., Stephan, S., & Ford, T. (2014). Mental health interventions in schools in high-income countries. *The Lancet Psychiatry*, 1(5), 377–387. [https://doi.org/10.1016/S2215-0366\(14\)70312-8](https://doi.org/10.1016/S2215-0366(14)70312-8)
- Gordillo, M. L., Chu, A., & Long, K. (2020). Mothers' adjustment to autism: Exploring the roles of autism knowledge and culture. *Journal of Pediatric Psychology*, 45(8), 877–886. <https://doi.org/10.1093/jpepsy/jsaa044>
- Headley, C., & Campbell, M. (2013). Teachers' knowledge of anxiety and identification of excessive anxiety in children. *Australian Journal of Teacher Education*, 38(5), 48–66.
- Hepburn, S. L., Blakeley-Smith, A., Wolff, B., & Reaven, J. A. (2016). Telehealth delivery of cognitive-behavioral intervention to youth with autism spectrum disorder and anxiety: A pilot study. *Autism*, 20(2), 207–218. <https://doi.org/10.1177/1362361315575164>
- Hepburn, S. L., Stern, J. A., Blakeley-Smith, A., Kimel, L. K., & Reaven, J. A. (2014). Complex psychiatric comorbidity of treatment-seeking youth with autism spectrum disorder and anxiety symptoms. *Journal of Mental Health Research in Intellectual Disabilities*, 7(4), 359–378. <https://doi.org/10.1080/19315864.2014.932476>
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Iruka, I. U., Winn, D. M. C., Kingsley, S. J., & Orthodoxou, Y. J. (2011). Links between parent-teacher relationships and kindergartners' social skills: Do child ethnicity and family income matter? *The Elementary School Journal*, 111(3), 387–408. <https://doi.org/10.1086/657652>
- Kerns, C. M., & Kendall, P. C. (2012). The presentation and classification of anxiety in autism spectrum disorder. *Clinical Psychology*, 19(4), 323–347. <https://doi.org/10.1111/cpsp.12009>
- Kerns, C. M., Kendall, P. C., Zickgraf, H., Franklin, M. E., Miller, J., & Herrington, J. (2015). Not to be overshadowed or overlooked: Functional impairments associated with comorbid anxiety disorders in youth with ASD. *Behavior Therapy*, 46(1), 29–39. <https://doi.org/10.1016/j.beth.2014.03.005>
- Kerns, C. M., Moskowitz, L. J., Rosen, T., Drahota, A., Wainer, A., Josephson, A. R., Soorya, L., Cohn, E., Chacko, A., & Lerner, M. D. (2019). A multisite, multidisciplinary Delphi consensus study describing “usual care” intervention strategies for school-age to transition-age youth with autism. *Journal of Clinical Child & Adolescent Psychology*, 48(sup1), S247–S268. <https://doi.org/10.1080/15374416.2017.1410826>
- Kerns, C. M., Renno, P., Kendall, P. C., Wood, J. J., & Storch, E. A. (2017). Anxiety disorders interview schedule–autism Addendum: Reliability and validity in children with autism spectrum disorder. *Journal of Clinical Child & Adolescent Psychology*, 46(1), 88–100. <https://doi.org/10.1080/15374416.2016.1233501>
- Last, C. G., & Perrin, S. (1993). Anxiety disorders in African-American and White children. *Journal of Abnormal Child Psychology*, 21(2), 153–164.
- Levitt, J. M., Saka, N., Romanelli, L. H., & Hoagwood, K. (2007). Early identification of mental health problems in schools: The status of instrumentation. *Journal of School Psychology*, 45(2), 163–191. <https://doi.org/10.1016/j.jsp.2006.11.005>
- Luxford, S., Hadwin, J. A., & Kovshoff, H. (2017). Evaluating the effectiveness of a school-based cognitive behavioural therapy intervention for anxiety in adolescents diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(12), 3896–3908. <https://doi.org/10.1007/s10803-016-2857-7>
- Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*, 51(3), 141–153. <https://doi.org/10.1352/1934-9556-51.3.141>
- Montes, G., Halterman, J. S., & Magyar, C. I. (2009). Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics*, 124(Suppl. 4), S407–S413. <https://doi.org/10.1542/peds.2009-1255L>
- Narendorf, S. C., Shattuck, P. T., & Sterzing, P. R. (2011). Mental health service use among adolescents with an autism spectrum disorder. *Psychiatric Services*, 62(8), 975–978. https://doi.org/10.1176/ps.62.8.pss6208_0975
- Pettygrove, S., Pinborough-Zimmerman, J., Meaney, F. J., Braun, K. V. N., Nicholas, J., Miller, L., Miller, J., & Rice, C. (2013). Predictors of ascertainment of autism spectrum disorders across nine US communities. *Journal of Autism and Developmental Disorders*, 43(8), 1867–1879. <https://doi.org/10.1007/s10803-012-1732-4>
- Reaven, J., Blakeley-Smith, A., Nichols, S., & Hepburn, S. (2011). *Facing Your Fears: Group Therapy for Managing Anxiety in Children with High-Functioning Autism Spectrum Disorders*. Baltimore, MD: Paul Brookes Publishing.
- Reaven, J., Reyes, N., Pickard, K., Tanda, T., & Morris, M. A. (2019). Addressing the Needs of Diverse Youth with ASD and Anxiety in Public Schools: Stakeholder Input on Adaptations of Clinic-Based Facing Your Fears. *School Mental Health*, 1–15.
- Reiss, S., Levitan, G. W., & McNally, R. J. (1982). Emotionally disturbed mentally retarded people: An underserved population. *American Psychologist*, 37(4), 361. <https://doi.org/10.1037/0003-066X.37.4.361>
- Rodgers, J., Wigham, S., McConachie, H., Freeston, M., Honey, E., & Parr, J. R. (2016). Development of the anxiety scale for children with autism spectrum disorder (ASC-ASD). *Autism Research*, 9(11), 1205–1215. <https://doi.org/10.1002/aur.1603>
- Salomone, E., Kutlu, B., Derbyshire, K., McCloy, C., Hastings, R. P., Howlin, P., & Charman, T. (2014). Emotional and behavioural problems in children and young people with autism spectrum disorder in specialist autism schools. *Research in Autism Spectrum Disorders*, 8(6), 661–668. <https://doi.org/10.1016/j.rasd.2014.03.004>

- Sanz-Cervera, P., Fernández-Andrés, M. I., Pastor-Cerezuela, G., & Tárraga-Mínguez, R. (2017). Pre-service teachers' knowledge, misconceptions and gaps about autism spectrum disorder. *Teacher Education and Special Education*, 40(3), 212–224. <https://doi.org/10.1177/0888406417700963>
- Scahill, L., Lecavalier, L., Schultz, R. T., Evans, A. N., Maddox, B., Pritchett, J., Herrington, J., Gillespie, S., Miller, J., Amoss, R. T., Aman, M. G., Bearss, K., Gadow, K., & Edwards, M. C. (2019). Development of the parent-rated anxiety scale for youth with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 58(9), 887–896. <https://doi.org/10.1016/j.jaac.2018.10.016>
- Sofronoff, K., Attwood, T., & Hinton, S. (2005). A randomised controlled trial of a CBT intervention for anxiety in children with Asperger syndrome. *Journal of Child Psychology and Psychiatry*, 46(11), 1152–1160. <https://doi.org/10.1111/j.1469-7610.2005.00411.x>
- South, M., Rodgers, J., & Van Hecke, A. (2017). Anxiety and ASD: Current progress and ongoing challenges. *Journal of Autism and Developmental Disorders*, 47(12), 3679–3681. <https://doi.org/10.1007/s10803-017-3322-y>
- Stahmer, A. C., Rieth, S., Lee, E., Reisinger, E. M., Mandell, D. S., & Connell, J. E. (2015). Training teachers to use evidence-based practices for autism: Examining procedural implementation fidelity. *Psychology in the Schools*, 52(2), 181–195. <https://doi.org/10.1002/pits.21815>
- Syriopoulou-Delli, C. K., Polychronopoulou, S. A., Kolaitis, G. A., & Antoniou, A. S. G. (2019). Views of teachers on anxiety symptoms in students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 49(2), 704–720. <https://doi.org/10.1007/s10803-018-3752-1>
- Tolan, P. H., & Dodge, K. A. (2005). Children's mental health as a primary care and concern: A system for comprehensive support and service. *American Psychologist*, 60(6), 601. <https://doi.org/10.1037/0003-066X.60.6.601>
- Vasa, R. A., Keefer, A., Reaven, J., South, M., & White, S. W. (2018). Priorities for advancing research on youth with autism spectrum disorder and co-occurring anxiety. *Journal of Autism and Developmental Disorders*, 48(3), 925–934. <https://doi.org/10.1007/s10803-017-3320-0>
- Voltz, D. L. (1994). Developing collaborative parent: Teacher relationships with culturally diverse parents. *Intervention in School and Clinic*, 29(5), 288–291. <https://doi.org/10.1177/10534512940290050>
- Walter, H. J., Gouze, K., & Lim, K. G. (2006). Teachers' beliefs about mental health needs in inner city elementary schools. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45(1), 61–68.
- Wood, J. (2006). Effect of anxiety reduction on children's school performance and social adjustment. *Developmental Psychology*, 42(2), 345. <https://doi.org/10.1037/0012-1649.42.2.345>
- Wood, J. J., McLeod, B. D., Klebanoff, S., & Brookman-Frazee, L. (2015). Toward the implementation of evidence-based interventions for youth with autism spectrum disorders in schools and community agencies. *Behavior Therapy*, 46(1), 83–95. <https://doi.org/10.1016/j.beth.2014.07.003>
- Zachor, D., Yang, J. W., Itzhak, E. B., Furniss, F., Pegg, E., Matson, J. L., Horovitz, M., Sipes, M., Chung, K.-M., & Jung, W. (2011). Cross-cultural differences in comorbid symptoms of children with autism spectrum disorders: An international examination between Israel, South Korea, the United Kingdom and the United States of America. *Developmental Neurorehabilitation*, 14(4), 215–220. <https://doi.org/10.3109/17518423.2011.568468>
- Zelege, W. A., Hughes, T. L., & Drozda, N. (2019). Disparities in diagnosis and service access for minority children with ASD in the United States. *Journal of Autism and Developmental Disorders*, 49(10), 4320–4331. <https://doi.org/10.1007/s10803-019-04131-9>
- Zuckerman, K., Friedman, N. D., Chavez, A. E., Shui, A. M., & Kuhlthau, K. (2017). Parent reported severity and health/educational services use among US children with autism: Results from a national survey. *Journal of Developmental and Behavioral Pediatrics*, 38(4), 260–268. <https://doi.org/10.1097/DBP.0000000000000437>