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Rebecca Harkema
Trinity Christian College

Gina Coffee
Loyola University Chicago, gcoffee@luc.edu

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Research-Based Practice

Anxiety Among Youth With Autism Spectrum Disorders: Current Research and Considerations for Practice

By *Rebecca Harkema & Gina Coffee*

Anxiety is experienced by children at various times throughout their childhood and adolescence, and can be a signal to them that something has gone awry in their environment or that their safety may be at risk (Hendrickx, 2010). Although certain levels of anxiety may be helpful, anxiety can become maladaptive when it consumes a child's life. For a child or adolescent with an anxiety disorder, this level of anxiety:

... has reached a point where it is no longer a useful indicator of danger ... but it is triggered by any minor event or thought to the point where it disables the person and impacts their life in a significant way (Hendrickx, 2010, p.127-128).

Current prevalence rates of autism spectrum disorders (ASDs) put forth by the Centers for Disease Control and Prevention estimate that 1 in 68 children is born with an ASD (Baio, 2014). Furthermore, among children diagnosed with an ASD, it is generally accepted that 40%-50% also have an anxiety disorder or anxiety related symptoms (Selles & Storch, 2012), making it one of the most common co-occurring disabilities experienced among individuals with an ASD (Rieske et al., 2012). In a review by van Steensel, Bogels, and Perrin (2011), it was found that the most common anxiety disorders experienced by individuals with an ASD are specific phobias (30%), obsessive-compulsive disorders (17%), agoraphobia (17%), generalized anxiety disorder (15%), and social anxiety disorder (9%). With the knowledge that anxiety can seriously impact the lives of children who already experience difficulties in social interactions, communication, restricted interests and repetitive behaviors (American Psychiatric Association, 2013), further discussion of current research and strategies that can be used to decrease the level of anxiety experienced by children with an ASD is warranted.

Impact of Anxiety in Autism Spectrum Disorders

Symptoms of anxiety can have a negative impact on the social, educational, and functional life of children and adolescents both with and without autism. Significant levels of anxiety in children can put them at risk for poor school achievement, difficulties with family and peer relationships, and substance abuse later in adolescent and adult life (Reaven, 2008). Ollendick and White (2012) suggest that there are shared features of anxiety between youth with and without an ASD and there are also unique indicators that are more prevalent among individuals with an ASD. Many children and adolescents experiencing anxiety display biased information processing, unhelpful thoughts, and physiological hyperarousal. However, some symptoms of anxiety for children with an ASD may look different from the indicators for typically developing children, and it would be beneficial for practitioners to be aware of these differences in order for supportive interventions to be implemented.

Among youth with ASDs, anxiety can manifest itself in extreme inflexibility, intense intolerance, and extreme avoidance of the various triggers associated with anxiety (Storch et al., 2012). Anxiety can also cause children and adolescents with an ASD to have difficulties with concentration, extreme fatigue, disturbed sleep, and excessive irritability (Reaven, 2008). Furthermore, Ollendick and White (2012) assert that other symptoms may include social confusion, heightened sensory defensiveness, weakness in perceiving emotions, negative or angry social interactions, and extreme difficulty with change. Finally, youth may display an increased insistence on rules and routines, engage in heightened levels of repetitive behaviors, or present with increased amounts of silly or explosive behaviors (Dasari, 2012).

These unique symptoms of anxiety can create difficulties for children with autism in educational and recreational settings and for adolescents in employment settings. When examining the social ramifications of anxiety in individuals with an ASD, White and Roberson-Nay (2009) found that youth with an ASD who reported heightened levels of anxiety on a self-assessment also reported heightened levels of social loneliness. Additionally, in a study conducted to understand the experiences of the anxiety of adults with ASDs, it was stated that participants reported that their "...anxiety represented not only an emotional or physical state, but also a key barrier to their participation in everyday activities, such as using public transport, meeting with friends, and attending school" (Trembath, Germano, Johanson, & Dissanayake, 2012, p. 222). Whereas adults with an ASD express that anxiety presents barriers to everyday activities, one must also consider the barriers anxiety creates for children with an ASD who may not be able to articulate their struggles.

Role of Anxiety in Autism Spectrum Disorders

The study of the role of anxiety in autism spectrum disorders has recently emerged in the literature. In a study by Mayes, Calhoun, Murray, and Zahid (2011), the response ratings of 627 mothers of children with ASDs were examined, and it was found that maternal ratings of anxiety levels in their children increased with the variables of verbal IQ of the child, age of the child, and severity of the ASD diagnosis. Additionally, mothers reported that elementary-age children experienced more anxiety than preschool children, and adolescent children experienced more anxiety than elementary children (Mayes et al.,

2011). Furthermore, in their study of young adults with an ASD, Trembath et al. (2012) found that the primary sources of anxiety were environmental factors, fear of an upcoming event or potential outcome, the possibility of disappointment, and interacting with others. Finally, Nasir and Tahir (2012) interviewed teachers and parents of seven children with autism (ages 4-18) and found that the common sources of anxiety were punishment, a barrier to a compulsion or stereotypical behavior, a change in the environment, or an unmet biological need. Common expressions of anxiety were crying, hyperactivity, defensive bodily positioning, clinging behavior, throwing of objects, and nail-biting.

The Role of Repetitive Behaviors and Restricted Interests in Anxiety

Recently, researchers have also studied the relationship between repetitive behaviors and restricted interests and levels of anxiety of children and adolescents with an ASD; that is, do restrictive and repetitive behaviors serve as coping mechanisms for already existing anxiety or do the heightened amounts of these repetitive behaviors actually cause the anxiety experienced by individuals with an ASD (Rodgers, Glod, Connolly, & McConachie, 2012)? With the knowledge that repetitive behaviors can significantly impact the social functioning and education of individuals with an ASD, it is necessary to understand the role of anxiety on these behaviors when designing interventions. For example, if the function of the repetitive behaviors was to serve as a coping mechanism for anxiety, practitioners would need to teach a replacement coping mechanism that interferes less with the social and educational functioning of the child but still provides coping support. On the contrary, if the repetitive behavior is actually causing more anxiety for the individual with an ASD, the intervention should target an appropriate fading of the repetitive behavior in order to hopefully reduce anxiety levels in the individual.

Rodgers, Glod, et al. (2012) studied the link between reported levels of anxiety and the severity of repetitive behaviors in 67 individuals with an ASD. Individuals with an ASD who had higher levels of anxiety also had higher levels of repetitive behaviors than those with lower levels of reported anxiety, and there was a significant correlation between the repetitive behavior component of insistence on sameness and the total anxiety score (Rodgers, Glod, et al., 2012). Similarly, research has been completed comparing the levels of anxiety and restricted and repetitive behaviors among youth with an ASD and among those with a diagnosis of Williams syndrome (Rodgers, Riby, Janes, Connolly, & McConachie, 2012). These two disability groups were chosen for comparison because both groups report heightened levels of anxiety among individuals and heightened levels of restricted and repetitive behaviors. A key difference between these two groups is that youth with an ASD can have withdrawn or awkward social interactions, while youth with Williams syndrome tend to be hypersocial.

The results of the study by Rodgers, Riby, et al. (2012) were that youth with an ASD had significantly higher levels of restricted and repetitive behaviors than children with Williams syndrome. Additionally, correlation analysis revealed that higher levels of restricted and repetitive behaviors were associated with elevated levels of anxiety in the group of students with an ASD. Because this same relationship was not present in the children with Williams syndrome, researchers contend that repetitive behaviors may have a very specific role in the "... development and maintenance of anxiety in ASD, compared to other groups..." (Rodgers, Riby, et al., 2012, p. 179). This research suggests that practitioners must consider the function of an individual's restricted and repetitive behavior in order to formulate an appropriate treatment plan, thereby testing if a reduction in an individual's restricted and repetitive behaviors reduces anxiety or if a reduction in anxiety reduces the level of restricted or repetitive behavior.

In addition to the relationship between repetitive behaviors and reported levels of anxiety, some work has indicated that engaging in restricted interests may provide an avenue for children with an ASD to find relief from their stress and anxiety. For example, Spiker, Lin, Van Dyke, and Wood (2012) found through correlation analysis that certain types of restricted interests were associated with symptoms of anxiety, and children involved with symbolic enactment were more likely to display symptoms of anxiety (Spiker et al., 2012). Additionally, it was revealed that spending more time with a restricted interest was only associated with the behavior of compulsive ordering. Significantly, the authors warned that measuring the time spent with a restricted interest is only one facet in understanding the relationship between restricted interests and anxiety. They suggest that "... manifestations of [restricted interests] that are more intense or take on specific (symbolically enacted) forms could be used as a shield or distraction for anxiety" (Spiker et al., 2012, p. 317).

Assessment and Intervention Considerations For Anxiety in Autism Spectrum Disorders

Considering that anxiety can cause social, academic, and functional barriers, children and adolescents with ASDs may benefit from anxiety-reducing interventions early in their lives. In particular, current research indicates that 18% of children with an ASD are diagnosed by the age of 3 and that most children are diagnosed by the age of 4 (Baio, 2012). Therefore, assessing levels of anxiety and providing early intervention strategies may provide the children with the supports that are needed.

It is beneficial for caregivers and practitioners working with children with an ASD to be aware of the signs and symptoms of anxiety that have been previously discussed, such as extreme inflexibility, disturbed sleep, excessive irritability, heightened sensory defensiveness, and explosive behaviors. Considering the aforementioned work of Mayes et al. (2011), those working with children and adolescents with an ASD should be attuned to the relative age group of individuals in order to recognize potential levels of anxiety, keeping in mind that elementary-age students may experience more anxiety than preschool students and adolescents may experience more anxiety than elementary-age students. For those working with younger children, it is important to be aware that youth may have an extremely difficult time expressing their anxiety, so that an increase in anxiety may manifest itself as an increase in challenging behavior (Minahan & Rappaport, 2013). Therefore, because the incidence of anxiety disorders in individuals with an ASD is elevated, and with the understanding that children may have difficulty expressing their emotions, it is recommended that all children with an ASD be screened for symptoms of anxiety in order to facilitate early identification of needs and responsive intervention (Mayes et al., 2011).

When completing the screenings and assessments, it is important to use multiple sources of information, including parent and child interviews, reliable and valid rating scales, and behavioral observations. Utilizing multiple sources of information is important because "[m]easures created for use with neurotypical children might not adequately capture symptoms of anxiety in youth on the spectrum, especially if anxiety is expressed in unusual ways" (White & Roberson-Nay, 2009, p. 1007). Additionally, children with an ASD may have difficulty completing self-assessments and rating scales of their own levels and experiences with anxiety; therefore, interviewing caregivers may help to provide additional information regarding the severity of the anxiety that the children may not be able to express (White & Roberson-Nay, 2009). In a review of 40 studies

of youth with anxiety and an ASD (White, Oswald, Ollendick, & Scanhill, 2009), the authors urged researchers to examine the applicability of traditional measures of childhood anxiety to the ASD population. In fact, they state, "Until we have consensus on 'best practice' measures, a healthy skepticism is called for with respect to the precision of the tools we currently have for measuring childhood anxiety when evaluating children with ASD" (White et al., 2009, p. 226).

Children with an ASD may have difficulty accessing treatment for anxiety due to a variety of obstacles that typically developing children may not encounter. Some of these include attention and social deficits, communication differences, disruptive behaviors, and poor adaptive skills (Selles & Storch, 2012). These potential barriers require that practitioners must give special consideration to the components of intervention and programming designed for students. For example, cognitive-behavioral therapy (CBT) has been found to be effective in decreasing anxiety in typically developing children and may provide an avenue of support if practitioners consider the specific strengths and needs of children with an ASD. The main components in CBT include "psychoeducation, somatic management, cognitive restructuring, problem solving, exposure, and relapse prevention ..." (Velting, Setzer, & Albano, 2004, p. 48) with the defining feature being a change in cognition as the mechanism of action (Beck, 1995). A modified version of CBT utilizing a more visual and concrete approach can be used with children with an ASD (Reaven, 2008).

These modifications include intentionally incorporating student strengths and interests into the program, providing multiple opportunities for practice in a variety of settings, including video modeling, using hands-on activities, and involving caregivers in the treatment. Furthermore, involving family members in treatment can give practitioners insight into specific behaviors that the child with an ASD may exhibit, and it can inform caregivers about how to structure the home environment in a way that supports the treatment plan (Selles & Storch, 2012). Although making modifications to CBT is not unique to the ASD population and can be helpful with children with other disabilities, it can be especially useful with children with an ASD.

Common strategies found effective in the education of children with an ASD can also be incorporated into CBT to allow children to access treatment. For example, Lang, Regeister, Lauderdale, Ashbaugh, and Haring (2010) encourage practitioners to incorporate social stories, relate emotions with tangible items, decrease the amount of abstract language, allow for alternative modes of communication, use technology, and emphasize a deeper focus on the teaching of social skills during CBT sessions with individuals with an ASD. In addition, Sung et al. (2011) found in their work with CBT and other forms of therapy, such as the use of a recreational social program, that important features of anxiety-reduction interventions for children with an ASD involved structured therapy sessions on a regular basis, consistent therapists working with each child, and strategies such as the incorporation of schedules and visual supports. Visually based supports are recommended for intervention programs for children with an ASD because visual processing seems to be an area of strength; its use decreases the reliance on deficit areas such as auditory processing and memory (Ganz, 2007). Giving children advance notice of what will be covered in therapy sessions can help them anticipate what to expect during the treatment session and thus decrease potential anxiety about unknown events. These added supports also can help students with other disabilities access treatment for their anxiety, but they are especially useful for the ASD population as these students require a predictable routine, knowledge of upcoming events or changes in plans, and information presented visually.

While clinicians deliver CBT in a therapeutic setting, it is important that school staff members are equipped with strategies to help a child with an ASD cope with anxiety throughout the school day since the child will typically spend more time at school than in a CBT session. Teachers are encouraged to be proactive in helping students manage their anxiety by implementing anxiety-reducing breaks throughout the day and planning for unstructured times (a typical trigger for anxiety in youth with an ASD) such as lunch, recess, and transition periods (Minahan & Rappaport, 2013). Teachers can also help children develop self-regulation skills by helping them to identify the progression of their emotions through the use of an "emotional thermometer." This is a visual tool that shows through pictures and graphics various emotions related with anxiety and provides a corresponding self-regulation strategy for the student (Minahan & Rappaport, 2013). Teachers are also encouraged to use *body checks*, which requires the teacher to narrate the behavior cues students are demonstrating to help them understand what an emotion looks and feels like for them. Finally, teachers should provide direct instruction and practice opportunities in self-calming skills because many students with an ASD do not know how to self-calm in anxiety-producing situations (Minahan & Rappaport, 2013).

Special Considerations

It is important to consider that children with an ASD diagnosis who also experience anxiety may have specific difficulties unique to the ASD population. Furthermore, practitioners should be aware that unique differences within individuals with an ASD might present specific challenges. For example, individuals with an ASD, anxiety, and a disruptive behavior disorder may have higher levels of reported anxiety than individuals with ASD and anxiety alone and may require specific modifications to an anxiety-reduction program. The incorporation of applied behavior analytic approaches within anxiety treatment may be helpful for children with an ASD, anxiety, and co-occurring behavior disorder as these methods have been used for children with autism that display challenging behavior (Storch et al., 2012). In addition, when working with a child with an ASD, anxiety, and a co-existing intellectual disability, strategies such as graduated exposure (based on observation or results of a fear-avoidance test), reinforcement (using a preference assessment), prompting (verbal or physical), and modeling (observing another child) may be effective because these treatments do not rely on receptive or expressive language skills (Hagopian & Jennet, 2008).

Conclusion

Anxiety related disorders are among the most common co-occurring disabilities for children and adolescents with autism spectrum disorders. Because anxiety can impact educational, vocational, and social areas of life, practitioners should be mindful of the specific indicators of anxiety and screen individuals at a young age to facilitate early identification and interventions designed to teach coping mechanisms. Attention is also needed to determine how to design interventions that are effective for the specific needs and strengths of children and adolescents with an ASD, that facilitate generalization across multiple environments, and that provide for the inclusion of parents and families in planning and implementing interventions.

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Rebecca Harkema is a doctoral student at Loyola University Chicago and an assistant professor of special education at Trinity Christian College in IL. Gina Coffee, PhD, NCSP, is an associate professor of school psychology at Loyola University Chicago.

National Association of School Psychologists, 4340 East West Highway, Suite 402, Bethesda, MD 20814
Phone: (301) 657-0270 | Toll Free: (866) 331-NASP | Fax: (301) 657-0275

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