

THE PARENT'S ROLE IN THE TREATMENT OF ANXIETY SYMPTOMS IN CHILDREN WITH HIGH-FUNCTIONING AUTISM SPECTRUM DISORDERS

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Anxiety disorders occur in children with autism spectrum disorders (ASD) at higher rates than in children with other developmental disabilities and children with typical development. Research on childhood anxiety supports cognitive-behavioral therapies as the treatment of choice to reduce anxiety symptoms. Parent involvement also positively impacts treatment outcome for these children. Research on the efficacy of psychosocial interventions for children with ASD and anxiety symptoms is sparse. This paper will review the literature on parental involvement in anxiety treatment and provide suggestions for involving parents of children who have both ASD and anxiety symptoms. Implications for future research will be offered.

Keywords: anxiety disorder, autism spectrum disorders, cognitive-behavioral intervention, developmental disability, dual diagnosis, intellectual disability, mental retardation, parents, psychiatric disorder

Anxiety disorders are among the most common psychiatric conditions that present during childhood.^{12,14,16,50} Symptoms of anxiety often co-occur with other diagnoses common in childhood, such as disorders of attention, mood, conduct and development.^{9,24,25} Children with autism spectrum disorders (ASD) are at high risk for developing comorbid psychiatric conditions, particularly anxiety disorders.^{3,18,36} In a study examining the co-occurrence of mental health symptoms in a group of children with high-functioning autism (HFA),³⁶ more than 80% of the children with HFA also presented with clinically significant co-occurring anxiety symptoms. In fact, the prevalence of anxiety disorders in children with ASD is higher than in children with other developmental disabilities and in children with a history of typical development.¹⁸

The development of anxiety symptoms typically involves the interplay between a number of variables including biological, psychological and environmental factors. Genetics, temperament, trauma and other adverse life events, as well as parenting behaviors, all influence the development of anxiety symptoms in children with average cognition.^{16,23,49} Although these factors are assumed to be critical in the development of anxiety symptoms in children with ASD, there is very little research that explores the developmental psychopathology of anxiety

symptoms in children with this complex developmental disorder.^{17,28} Similarly, treatment research on co-morbid anxiety and ASD focuses primarily on psychopharmacological intervention with little attention given to psychosocial interventions.⁴⁰

The purpose of this paper is to review the literature concerning parental involvement in the treatment of childhood anxiety and provide treatment recommendations for parents of children who are dually diagnosed with autism and anxiety. High-functioning children are the focus of this paper, because their cognitive and language abilities are most similar to children with anxiety disorders in the general population. Certainly, children who are less verbal or less intellectually capable experience anxiety as well; however, the treatment approaches reviewed herein are most appropriate for children who are verbally fluent.

In order to provide empirically sound suggestions for parents of children with comorbid ASD and anxiety, we must first turn to the research outlining the treatment of childhood anxiety, with an emphasis on the parent's role in the treatment process. Overall, the literature does support the efficacy of focused parental involvement in the treatment of children with anxiety disorders^{5,12,35,48} especially for prepubertal children (i.e., 7-10 years of age). As the focus and content of parental involvement is reviewed for

children in the general population, the applicability of these interventions and suggestions for parents of children with both ASD and anxiety will be discussed.

TREATMENT OF CHILDHOOD ANXIETY

Countless children experience a number of sub-clinical anxiety symptoms throughout their childhood. What differentiates these children from children diagnosed with anxiety disorders is not the content of their symptoms, but rather the severity of their presentation.⁴³ Not only do anxious children experience symptoms that markedly interfere with day to day functioning, but these symptoms are persistent, cause much distress and are excessively time consuming. Chansky¹⁰ adds that anxiety symptoms are more likely to become a disorder when a child overestimates dangerousness **and** underestimates his ability to cope with a given situation. Thus, non-anxious peers experience the same fears and worries as their anxious counterparts, but it is the reaction to these symptoms that ultimately differentiates the children.¹⁰

Many clinical researchers now concur that cognitive-behavioral therapy (CBT) is the treatment of choice for children with internalizing disorders, including the symptoms of anxiety and depression.^{12,50} CBT for treatment of anxiety symptoms generally consists of six essential components: *psychoeducation, somatic management, cognitive restructuring, problem solving, exposure and relapse prevention.*⁵⁰

Psychoeducation involves explaining to the child and his/her family the nature of the anxiety symptoms, as well as providing an overview and rationale for treatment. Clearly, the explanation of anxiety should be tailored to the child's level of development, and can include the identification of factors that contribute to the development of symptoms (i.e., biological correlates, stressful life events, etc.).⁴⁹

Further, many researchers agree that the interplay between the physiological components of anxiety, cognitions (beliefs, assumptions) and behavior (avoidance or escape of fearful situations) contributes to the development of anxious symptoms.⁵⁰ As a result, relaxation strategies and other calming activities are introduced. Additionally, strategies to challenge existing thoughts and distorted cognitions are taught directly to children with anxious symptoms.¹⁰ Further, rank ordering fearful

situations, and implementing imaginal and/or in vivo exposure for the fearful situations, is believed to be one of the most critical components of CBT interventions.²⁶ Finally, the inclusion of specific relapse prevention strategies, such as establishing specific procedures for handling the recurrence of symptoms as well as the scheduling of booster sessions, has promoted generalization and maintenance of treatment gains in children with anxiety disorders.⁵⁰

THE IMPACT OF PARENT PARTICIPATION IN THE TREATMENT OF CHILDHOOD ANXIETY

The power and positive impact of parental participation in the treatment of childhood anxiety disorders is well documented.^{6,11,14,35,46} The general conclusion from these studies is that parental involvement coupled with CBT interventions can enhance the treatment effectiveness for children with anxiety disorders.^{11,35} While studies evaluating the efficacy of different treatment conditions (i.e., Child Alone, Child Plus Parent Condition) indicate that children in both conditions, responded positively to the interventions, more children in the Child/Parent condition demonstrated greater reductions in symptoms than the children in the Child Alone group. In addition, the reduction in anxiety symptoms in children whose parents participated in treatment were maintained at 6 month and 12 month follow-up visits, particularly for prepubertal children (ages 7-10). The sustained benefits of parental involvement in treatment present for younger children were less noticeable at follow-up for older children (ages 11-14).⁶ Further, the usefulness of a family/parent component in the maintenance and generalization of therapeutic gains for children presenting with childhood anxiety is generally supported when intervention is delivered both individually⁶ and in group formats,^{6,35} although the characteristics of treatment responders in different treatment modalities is unclear.

THE PARENT'S ROLE IN TREATMENT

There is consensus in the literature concerning the essential components of parental involvement in treatment. Most of the studies that have included a family intervention component comprised of the following elements:^{6,11,35} 1) Teach parents to reward courageous behaviors and extinguish excessive anxiety in their children; 2) Increase parental awareness of their own anxiety

symptoms and the extent to which they may play a role in the development and maintenance of anxiety symptoms in their children; 3) Teach parents to model effective problem-solving and proactive responses when they experience their own anxiety symptoms; and 4) Teach both parents (if possible) to work together as a couple in their child-rearing practices.

TREATMENT OF ANXIETY SYMPTOMS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS

Given the co-morbidity of anxiety and autism spectrum disorders, it is surprising that so few treatment studies of dually diagnosed persons exist in the literature. In fact, research using randomized clinical trials to examine the effectiveness of CBT protocols has typically excluded children with pervasive developmental disorders.^{6,11}

Psychopharmacological interventions are more commonly described in the research for individuals with autism spectrum disorders, than psychosocial interventions. For example, several studies illustrating the effects of medications on adults with obsessive-compulsive disorder and autism have been reported.^{15,34} Hollander *et al.*²² have also explored the use of psychopharmacological treatments aimed toward reducing anxiety symptoms in persons with autism, and report modest symptom improvements.

Studies of cognitive-behavioral therapies for anxiety in persons with ASD are rare, but promising. Lord²⁹ documented the successful treatment of obsessive symptoms in an adolescent male with autism utilizing traditional cognitive-behavioral strategies. Hare²¹ described the use of cognitive-behavioral therapy to treat anxiety and depression in a 26-year old dually diagnosed male.

In addition to these accounts, several published studies also highlighted the importance of parent participation in the treatment of their children with dual diagnoses. Love *et al.*³⁰ utilized graded exposure techniques (a component of CBT practice) to alleviate excessive fears in two young people with autism. The reduction in anxiety symptoms for two young children (ages 4 and 6) with autism spectrum disorders were successfully achieved in large part because they were treated by their mothers using behavioral strategies such as graded exposure and contingent reinforcement

to treat specific fears. We published a case study on modification of cognitive-behavioral strategies to treat obsessive-compulsive disorder in a 7-year old with Asperger syndrome.⁴⁰ Receptivity to the protocol, and generalization of treatment benefits were in large part due to parental involvement in treatment. Sofronoff *et al.*⁴⁵ implemented a brief (six week) group CBT intervention to reduce anxiety symptoms in children ages 10-12 with Asperger syndrome. The results suggest that the CBT program was effective in reducing anxiety symptoms both immediately after treatment and at a three-month follow-up. This study also found that parental involvement in the treatment protocol yielded greater reductions in parent-reported anxiety symptoms.

Thus, although we recognize that parental involvement in the treatment of children with ASD and anxiety symptoms is important, specific behavioral recommendations for these families has been lacking in the literature. In the section that follows, we will review factors unique to children with ASD and their parents, and suggest modifications of best practice interventions for childhood anxiety, for families of children with ASD. Parental stress and parental anxiety in families of children with autism will be briefly examined. In addition, the intersection of these parenting behaviors with the core deficits of autism will be discussed and a framework for treatment considerations in light of these factors will be offered.

CONSIDERATIONS FOR CHILDREN WITH ASD AND THEIR FAMILIES

PARENTING STRESS

It is well known that parenting a child with ASD can be a tremendous challenge, but parenting a child who presents with ASD as well as marked anxiety symptoms can be even more daunting.⁴² Parental competence is challenged from the onset, as traditional parenting strategies may be ineffective for children with ASD. In fact, maternal stress may be most influenced by their children's behavior problems rather than autism symptoms alone.²⁰ There is also evidence of bi-directionality for mothers and children with intellectual disabilities (including autism)—as behavior problems worsen, so does marital distress, and as marital distress worsens, so do children's challenging behaviors.¹⁹

For some families, the agonizing process of identifying what is "wrong," and successfully

finding an accurate diagnosis is enough to thwart parental confidence, particularly if their children are high-functioning.³⁹ In addition, completing daily family routines is challenging, in that parents of children with autism have continual responsibilities, with limited periods of respite. It is not uncommon for parental isolation and loneliness to result. Parents of children with autism also face chronic stress in the search for appropriate treatments for their children.^{33,44}

PARENTAL ANXIETY

Adding to the increased stress for parents of children with ASD, parents of children on the autism spectrum are at increased risk for experiencing clinically significant anxiety symptoms themselves. Whether these symptoms exist pre-morbidly prior to the diagnosis of autism in their children is still unclear. Studies describing the “Broader Autism Phenotype” (a lesser variant of Autistic disorder⁴) suggest that relatives of individuals with ASD are at increased risk for a variety of cognitive and personality traits, including anxiety symptoms and obsessive-compulsive disorder.³⁷

Parental anxiety can impact child functioning. Barrett⁵ reports that anxious children and their anxious parents make relatively high numbers of threat interpretations when presented with ambiguous situations or stimuli. When anxious individuals perceive stimuli as potentially dangerous, avoidant behavior becomes a primary coping strategy. The connection between the interpretation of incoming stimuli (i.e., threat) and coping strategies (i.e., avoidance) is an important one, since parental tolerance of avoidance allows the perpetuation of avoidant behavior and decreases opportunities to develop alternative coping techniques.^{13,14,31} Therefore, an anxious parent may promote avoidant coping strategies. A failure to develop a broad repertoire of coping strategies can also lead to a decreased sense of mastery or competence, resulting in further avoidance of challenging situations.^{23,27} Clearly, a circular pattern of cognition and behavior can develop. (see Figure A)

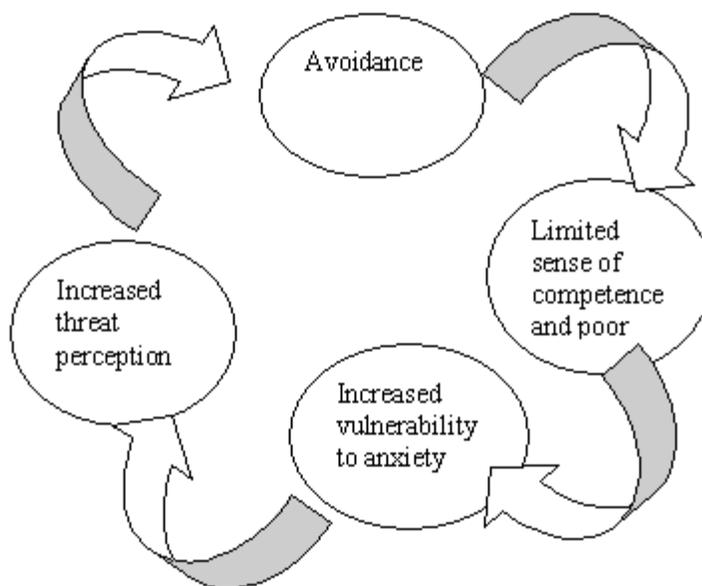
CORE DEFICITS OF ASD

Children with autism spectrum disorders present with pervasive deficits in social, communication and play behaviors.^{1,2} The core deficits of ASD exacerbate the onset of anxiety symptoms, and the social, cognitive and

communicative challenges inherent in autism spectrum disorders further impede the ability to generate effective coping strategies for handling problematic situations.²⁸ When children with ASD experience clinically significant anxiety, parents and professionals need to identify the autism-specific core deficits that contribute to the anxious behaviors, as well as the cognitions (i.e., negative thinking, cognitive distortions) and behaviors (i.e., avoidance) that result in excessive displays of anxious symptoms. Targeting both skill development as well as “facing fear” through graded exposure, may be critical for children with ASD. Beidel, *et al.*'s⁷ treatment model for social anxiety (Social Effectiveness Therapy for Children; SET-C) is particularly relevant in that these authors purport that an effective intervention for social anxiety is to directly target **both** the social skills deficits, as well as the concurrent anxiety symptoms through cognitive restructuring, somatic management and graded exposure.⁸

INTERACTION BETWEEN ASD CORE DEFICITS AND PARENTING BEHAVIORS

As parents more fully understand their children's symptoms, they can begin to look at the interaction between their own parenting behavior and their children's abilities. We would argue that the interplay between the core deficits of children with ASD and social and environmental demands engender either *adaptive protection* or *excessive protection* in their parents. *Adaptive protection* can be defined as a functional parental response that occurs when children present with marked areas of developmental, physical or emotional challenge, and in reaction to these challenges, parents and other caregivers titrate their children's exposure to demanding environmental events to create success experiences. *Excessive protection*, on the other hand, is a parental response that restricts a child's exposure to anxiety provoking situations through avoidance even when children, in spite of their limitations, possess the necessary skills for success. Thus, *excessive protection* may limit the opportunity for children to generate and practice effective coping strategies for handling anxiety symptoms. Because of their social and communicative challenges, as well as the vulnerability of children with ASD to the development of anxiety symptoms, the distinction between *adaptive protection* and *excessive protection* may become blurred. Parents may

FIGURE A. IMPACT OF ANXIETY ON COPING BEHAVIORS

need the assistance of an experienced clinician to provide diagnostic information regarding the presence of anxiety symptoms or disorders, differentiate when protection is necessary, determine the skill set that may need to be taught, and receive direction on how to coach their children to handle stressful events.

RECOMMENDATIONS FOR PARENTAL INVOLVEMENT IN THE TREATMENT OF CHILDREN WITH ASD AND ANXIETY DISORDERS

It is clear that parental involvement in the treatment of anxiety symptoms for children with ASD may be a powerful, but as of yet, untapped resource. Recommendations based on clinical experiences and integration of the clinical literature, for parents of children with high-functioning autism spectrum disorders and anxiety symptoms are outlined below.

1. Provide psychoeducation about anxiety disorders.

As noted earlier, developmentally appropriate explanations to the child and his/her family regarding the genesis of the anxiety is an essential first step. “Externalizing” the anxiety symptoms for the child and discussing these symptoms as separate and distinct, can be a helpful strategy in

promoting a sense of competence. A supportive “team” (parents, therapists, siblings) can then be established to support the child in “beating” anxiety.^{32,47} An emphasis on the child’s strengths and abilities is essential so that children and their parents are able to access their strengths and courage to resist anxious feelings and face fears.

2. Implement cognitive-behavioral strategies.

Well-established CBT strategies, such as increasing self-awareness of anxiety symptoms and triggering events, use of graded exposure, cognitive restructuring, relaxation and other strategies for reducing physiological arousal, need to be considered for children with ASD and anxiety. Modifications to traditional CBT protocols will likely be required to enhance effectiveness^{40,41} of these strategies. For example, prerequisite skills including a good working vocabulary of emotions or feeling words may need to be taught before children with ASD can take advantage of the components of a CBT protocol.⁴⁵ Additionally, the majority of existing CBT protocols are highly verbal, and may not be well-suited for children with ASD. Thus, when introducing basic principles of CBT to children with ASD, the use of written worksheets and hands-on activities (i.e., arts and crafts), may make the new information more salient. Much repetition and practice throughout

the interventions will likely be required to promote learning.

The pacing of the therapy sessions may also be critical to consider. Careful structuring and pacing of the therapy sessions are essential to maintain attention, and to support the children without allowing them to become too overwhelmed by content. Visual structure and predictability of routine within session, frequent breaks, interspersing CBT content with areas of special interest, as well as reinforcement for participation have all been helpful in our clinical experience.⁴¹

Relapse prevention strategies are essential to sustain the benefits of treatment for all children. For children with ASD, making videos of themselves “facing fear” as a reminder of how they identified their worries, and implemented strategies to fight fear a little at a time (graded exposure) may be a useful activity. The scheduling of booster sessions for parents and/or children where concepts of CBT are reviewed may also be helpful in relapse prevention.

3. Treat core deficits of ASD.

Although not a completely causal relationship, the core deficits of ASD likely contribute to the development of anxiety symptoms for children.²⁸ Deficits in social and communicative areas combined with ever changing social and environment expectations set the stage for the onset of anxiety symptoms (genetic transmission of symptoms notwithstanding). The use of evidence-based strategies directed at the core symptoms of ASD will not only improve skill development across all areas of functioning, but may indirectly thwart the onset of anxiety symptoms. Applied behavior analysis, environmental modifications, visual strategies and support, functional behavior assessment and positive behavior supports are recommended to address the deficits in social/communication, and to promote organization and independence skills.³⁸

4. Understanding parenting behavior—adaptive protection versus excessive protection.

A careful exploration of the child’s physical, social and communicative challenges as well as his strengths and talents is an important first step when addressing parenting behavior. The extent to which the child requires “protection” in light of his strengths and deficits must be directly addressed, and issues of child safety and independence, as well as parental concerns, must be carefully

balanced. Because parental anxiety affects parenting style,^{6,31} frank discussions reviewing the extent to which parental anxiety is a factor, are essential. Should parents confirm anxiety symptoms for themselves, it is important to support them as they work towards management of their anxiety symptoms. When parental anxiety is handled well, parents are better able to directly model courageous behavior, extinguish their child’s excessive anxiety and express confidence in their child’s ability to handle anxiety symptoms and feared situations. Involving both parents as much as possible in the treatment process is also recommended.

5. Promote generalization of skill development and coping strategies across settings.

Generalizing new skills across settings does not happen easily for children with ASD. Additionally, there are often a number of different professionals and family members involved in the care and treatment of children with ASD. Ongoing and informative communication between all of the important players (parents, school staff, and private therapists) is critical in enhancing the maintenance and generalizability of new skills and techniques.

SUMMARY

Anxiety disorders and autism spectrum disorders are highly co-occurring. Multiple factors influence the development of anxiety symptoms in ASD, not the least of which may be the core deficits of the disorder—making these children vulnerable to stress and an ever changing environment. Further contributing to the mix is a set of parental factors and influence. A challenging diagnostic process, confusing messages from the professional community, as well as intense behavioral needs due to the impact of anxiety symptoms on their child’s presentation, all can negatively impact on the parents’ sense of competence. Furthermore, the research suggests a strong connection between parental anxiety and anxiety disorders in their offspring. When parental anxiety is present, in some cases it can lead to parental protection, and while adaptive in many cases, at times protection may become excessive. When parental protection is excessive, children have limited opportunities to struggle with feared situations, and thus have fewer opportunities to develop and/or practice effective coping strategies. While adaptive protection is no doubt critical in the

parenting process for children with both ASD and anxiety symptoms, supporting children to face their fears is essential for symptom reduction. Knowledge and effective implementation of CBT approaches, acknowledgment and awareness of the parenting role, coupled with fluid communication between parenting partners and professionals may effectively reduce symptoms of anxiety in children with autism spectrum disorders.

Future directions can include not only continuing to explore the empirical validity of CBT approaches for children with ASD and anxiety delivered in individual and group contexts, but include identification of critical components of parental involvement that may promote and sustain reduction in anxiety symptoms.

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