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WITH AUTISM: PAVING THE WAY TO EVIDENCE-BASED
PRACTICE**

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COGNITIVE-BEHAVIORAL THERAPY FOR ANXIETY IN YOUTH WITH
AUTISM: PAVING THE WAY TO EVIDENCE-BASED PRACTICE

A dissertation submitted in partial fulfillment

of the requirements for the degree of

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ABSTRACT

COGNITIVE-BEHAVIORAL THERAPY FOR ANXIETY IN YOUTH WITH AUTISM: PAVING THE WAY TO EVIDENCE-BASED PRACTICE

Michelle M. Kirkland

Anxiety is one of the most common and debilitating conditions co-occurring with autism spectrum disorder (ASD) as it occurs in up to 84% of individuals and can influence poor psychosocial adjustment, disruptions in individual, familial and school functioning, increased emotional and behavioral problems, self-injurious behavior(s), and an overall reduced quality of life (Meyer, Mundy, Van Hecke, & Durocher, 2006; Nadeau et al., 2011; Farrugia & Hudson, 2006; Kerns et al., 2015). To date, cognitive-behavioral therapy (CBT), an evidence-based treatment for anxiety in neurotypical youth, has seen modest, yet limited, promise in treating anxiety in youth with ASD. With extant research lacking consistency, replication, and focus on the unique barriers impacting treatment in the ASD population, this study examines clinical experiences in conducting CBT for anxiety in these youths in hopes of identifying treatment limitations and modifications in need of future study (Selles & Storch, 2013; Vasa et al., 2014; Chalfant et al., 2007, Wood et al., 2009). Results indicate that the most common treatment barriers in this population include: (a) the severity and associated impairment of the anxiety, (b) the limited interpersonal, cognitive, perspective-taking, and executive functioning skills of the youth themselves, (c) the youth's cognitive and behavioral rigidity, (d) a dysfunctional home environment, (e) lack of youth motivation for treatment, and (f) the time constraints associated with treating this population.

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Chapter 1

Introduction

Statement of the Problem

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by persistent deficits in social interaction and communication, such as difficulty initiating and sustaining nonverbal (e.g., eye contact) and verbal (e.g., social reciprocity) communication resulting in failures in developing and maintaining age-appropriate relationships, and patterns of stereotyped behaviors, interests and activities (American Psychiatric Association, 2013). Most recently, the Center for Disease Control and Prevention estimated that approximately one in 59 children in the United States (US) are diagnosed with ASD, with male diagnosis four times more likely than that of females (Barnard-Brak, 2019). Approximately 75% of individuals with autism also meet diagnostic criteria for at least one psychiatric disorder, of which one of the most common and impairing is anxiety (Simonoff, Pickles, Charman, Chandler, Loucas & Baird, 2008). This paper reviews existing research on the impact of anxiety on the social, emotional, behavioral, and cognitive functioning of youth with ASD. Current interventions are discussed thereafter. This study aims to gather clinical feedback regarding treatment limitations for anxiety in this population to aid in the development of evidence-based practices.

Chapter 2

Literature Review

ASD and Anxiety

Research suggests that approximately 40% of individuals with ASD meet the criteria for an anxiety disorder compared to three to eight percent of typically developing persons (Van et al., 2011; Matson & Cervantes, 2014). Though differing by study, the following are prevalence rates at which persons with autism experience various anxiety presentations: 8.5-44.3% experience specific phobia (SP), 7.4-29.2% social anxiety disorder, 6.4-37% obsessive-compulsive disorder (OCD), 6.4-7.9% agoraphobia, 2.4-13.4% generalized anxiety disorder (GAD), 1.1-10.1% panic disorder, and 0.5-12% separation anxiety disorder (Selles & Storch, 2013). Children with ASD are more than two times more likely to develop an anxiety disorder than typical peers, children with attention-deficit/hyperactivity disorder (ADHD), and those with learning difficulties, and have significantly higher anxiety severity ratings than psychiatric clinic referrals, general education and special education students (Weisbrot et al., 2005). Significantly more cases of general and social anxiety disorder were also found in individuals with lower intelligent quotients (IQ), while those with higher IQs had higher rates of OCD and separation anxiety disorder. Therefore, Van Steensel et al. (2011) suggest that individuals with ASD and an IQ between 70-87 may be at a heightened risk for anxiety disorders (Kuusikko, 2008; Lecavalier, 2006; Costello et al., 2005; Gau et al., 2010; Dekker & Koot, 2003).

White et al. (2009) further expressed that up to 84% of children with ASD experience some degree of impairing anxiety. Their meta-analysis included 31 studies and evaluated 2,121 participants with a diagnosis of autistic disorder (AD), Asperger's

Syndrome (AS), or pervasive developmental disorder-not otherwise specified (PDD-NOS), and, at least, one anxiety disorder. They concluded that higher rates of OCD and SP occurred with a diagnosis of AD than with any other autism-related diagnosis or for neurotypical individuals. Additionally, GAD was observed in AS, and SP, GAD, and panic disorder seen in PDD-NOS.

For those with autism, levels of intellect and communication, as well as increases in age, positively correlate with anxiety severity, and older adolescents are more likely to report anxiety, specifically GAD. Contributing factors may be increases in awareness and articulation abilities, as well as increases in platonic and romantic social pressures, and focus on physical appearance, academic performance, and independency, respectively (Weisbrot et al., 2005; Davis et al., 2011; Van Steensel et al., 2011).

Anxiety frequently manifests differently in youth with ASD, and this, along with the high frequency of anxiety in this population, contributes to difficulties in determining if certain problem behaviors are characteristics of ASD or anxiety, as some believe anxiety is “better explained by the ASD itself”. For example, while social avoidance could result from fear of rejection in typical populations, those with ASD might socially avoid because of social confusion or lack of, or fear of self or others breaking, rules. Autism is also related to ambiguous or “odd” worries such as fear of schedule changes or unusual stimuli such as toilets (Selles & Storch, 2013; Kerns et al., 2016). Kerns et al. (2014) assessed the prevalence of “traditional” anxiety symptoms/disorders as outlined in the DSM-5 and the “atypical” anxiety symptoms more so related to ASD in a sample of 59 participants aged 7-17-years-old with ASD. They found that of the 63% of individuals exhibiting anxiety symptoms, 48% showed “traditional” symptoms, and 15% “atypical”.

It was noted that language-ability was associated with “traditional” symptoms, and ASD-severity with “atypical” presentations (Kerns et al., 2014). As such, Hagopian and Jennett (2014) differentiated “simple avoidance”, avoidance of non-preferred stimuli or locations, from “anxious avoidance”, avoidant behavior accompanied by traditional anxiety symptoms like fearful facial expressions and physiological arousal.

More so, Kelly et al. (2008) found, after controlling for IQ, communication level, age, gender, and the number of siblings with ASD, that anxiety and depressive symptoms were positive predictors of core autism symptom severity. This is exemplified by the fact that youth with high functioning autism (HFA) are more likely to experience more significant distress in social situations due to both the social limitations characteristic of ASD, and the awareness of their social deficits and likelihood for failure. Because of this, a bi-directional impact is seen between ASD and anxiety symptomology as this distress influences these youth to avoid social situations and lose social learning opportunities (Bellini, 2004; Griswold & Simpson, 2001). Social communication anxiety further influences academic impairments, less participation in school activities, and predicts academic failure as youth with autism do not seek social or verbal learning opportunities and, subsequently, do not learn from their environment(s) (Fleury et al., 2014). Social impairment is said to be a stronger predictor of poor reading comprehension than word recognition or oral language deficits since it impacts perspective-taking skills needed in reading and writing (Fleury et al., 2014; Brown et al., 2013).

Other limitations to anxiety assessment and treatment in these individuals are the inability of providers to directly observe anxiety-related cognitive, affective and physiological arousal states, the difficulty of these youth to self-report, and the

simultaneous demonstration of presentations like anxiety, social impairment, restricted repetitive behaviors (RRBs) and aggression (White et al., 2009; Groden et al., 1994; Moskowitz et al., 2013). Although intervention is complicated for these reasons, such diagnostic overshadowing precludes this population from evidence-based intervention for difficulties proven distinct by qualitative research and comparable, or exceeding, clinical anxiety rates of typical youth (Selles & Storch, 2013; Moskowitz et al., 2013; Kerns et al., 2016).

Due to anxiety, children with ASD experience more inadequate psychosocial adjustment, more disruptions in individual, familial and school functioning, and increased emotional and behavioral (e.g., defiance) problems, self-injurious behavior(s), rejection, loneliness, sleep disturbances, parental stress and reduced self-image/confidence (Meyer et al., 2006; Nadeau et al., 2011; Farrugia & Hudson, 2006; Kerns et al., 2015). Upon review of 15 studies, White et al. (2009) concluded that, significantly more than typical comparisons, youth with ASD had higher correlations between anxiety and behavior problems, negative automatic thoughts, and overall life interference.

ASD, Anxiety, and RRBs

RRBs are the second core symptom of ASD and are noted by parents as the most challenging symptoms to manage (South et al., 2005). This term refers to a wide range of behaviors, activities, and interests reflective of cognitive and behavioral rigidity, such as stereotyped or repetitive motor movements (e.g., hand flapping), use of objects or speech (e.g., vocal stimming), inflexibility to routine changes, ritualized behavior, perseverative interests, and hyper- or hypo-reactivity to sensory stimuli (American Psychiatric Association, 2013). The literature separates categories of RRBs into two-factor models—

discriminating between the repetitive sensory-motor (RSM) and insistence on sameness (IS) behaviors—and more nuanced three, four and five-factors models that categorize these actions into sensory-motor, self-injurious, compulsive, restricted interests, and ritualistic/sameness domains (Szatmari et al., 2006; Lidstone et al., 2014; Bishop et al., 2013).

Comorbid anxiety has shown to correlate with higher frequencies and intensities of RRBs for individuals with high- and low-level IQs (Sukhodolsky et al., 2008; Van Steensel et al., 2011). Research has evidenced high associations between anxiety and self-injurious behaviors, IS, ritualistic and inflexible behaviors, and circumscribed interests (Kerns et al., 2015; Russell et al., 2019; Stratis & Lecavalier, 2013; Cervantes et al., 2013; Rodgers et al., 2012; Lawson et al., 2015; Black et al., 2017). More so, IS behaviors are believed to be mediated by intolerance of uncertainty (IU), or negative perceptions of ambiguous situations, and are seen as a means to gain control over the environment—thus viewing RRBs as a coping mechanism for anxiety. Studies have shown that certain types of RRBs and interests like symbolical enactment and attachment to objects are associated with higher anxiety levels in children with autism, while others like factual/verbal repetition are not (Joyce et al., 2017; Wingham et al., 2015; Spiker et al., 2011).

ASD, Anxiety, and Aggression

Furthermore, approximately 50% of individuals with ASD exhibit aggression, which is commonly defined as hitting, kicking, biting, throwing objects or pulling hair directed at another person. In a study of 1,350 children and adolescents with ASD,

approximately 68% were reported by their parent(s) to demonstrate aggression towards caregivers and 49% towards non-caregivers (Kanne & Mazurek, 2011).

Antecedents of aggression are ASD symptoms such as poor communication and cognitive rigidity. However, meta-analytic reviews found that anxiety regarding feared stimuli also evokes aggression, and that individuals having both ASD and an anxiety disorder are more likely to engage in aggressive behaviors (Matson & Adams, 2014; Van Steensel et al., 2011; White et al., 2009). Specifically, Evans et al. (2005) matched children with ASD to children diagnosed with Down Syndrome (DS) via cognitive age. Children with ASD were also matched with neurotypical controls via chronological age. Results found that externalizing behavior problems of youth with ASD were more related to children's anxieties, and desired avoidance of them, than for either of the comparison groups. Such fears were of large crowds and public transportation more so than for typical persons of whom feared failure or punishment. Specifically, for children with ASD, situational (e.g., crowds, school bus), harm-related, and social (e.g., meeting peers and fear of strangers) fears correlated with anxiety, as well as with conduct problems, learning problems, and hyperactivity (Evans et al., 2005; Matson & Love, 1990). Research thus suggests that anxiety might be an internal antecedent to problem behaviors like aggression, and may be functionally linked to maladaptive behaviors due to engagement in aggression to avoid, escape or reduce anxiety (i.e., reductions in problem-behaviors in children with ASD were seen after they received an intervention to reduce fear and/or anxiety; Romanczyk & Matthews, 1998; Moskowitz et al., 2013; Bronsard et al., 2010).

Studies by Ambler et al. (2015) and Pugliese et al. (2013) found that social anxiety was positively correlated with physical aggression in adolescents with ASD and was commensurate to levels in clinical controls. This social anxiety also resulted in aggression similar to clinical referrals with oppositional defiant disorder (ODD). Research suggests that higher rates of RRBs are associated with frequent aggressive behavior, as studies evidence links between aggression and resistance to change, inflexibility and IS behaviors, and cognitive rigidity. As such, RRBs are thought to be a predictor of aggression in individuals with ASD (Kanne & Mazurek, 2011; Lawson et al., 2015; Matson & Adams, 2014). Though direct associations between anxiety, aggression and RRBs in persons with ASD have not been directly tested, preliminary support for this three-way relationship was given by Lawson et al. (2015). Authors tested and supported a relationship between inflexibility, anxiety and aggression through parent reports of executive functioning and behavior via the Behavior Rating Inventory of Executive Function (BRIEF) and the Child Behavior Checklist (CBCL) for 70 children with ASD aged six to 16 years-old (Lawson et al., 2015).

Aggression is the strongest predictor of crisis intervention re-referrals, suspensions, admission and re-admission to residential facilities and out-of-school placements, psychotropic medication use, need for physical restraint(s), parental stress, physical abuse from caregivers and a reduced quality of life (Kanne & Mazurek, 2011).

Interventions for Youth with Anxiety and ASD

With a possible diagnosis as early as 12 months, students between the ages of 3-21 years-old holding the autism classification comprised approximately 10% of students served under the Individuals with Disabilities Education Act (IDEA) in public schools

within the 2017-18 academic year, and approximately 65% of students with developmental delays, including autism, spent 80% or more of school time in general education settings (McDonald, Donnelly, Feldman-Alguire, Rodgers, Lopata & Thomeer, 2019). Schools are then seen as the “ideal location of choice” for delivery of mental health services for individuals with autism due to the amount of time spent in school, proximity to the home, minimal, or no, financial requirements, and ecological validity allowing for enhanced generalization of skills in settings that are typically most challenging (Drmic, Aljunied, & Reaven, 2017). However, a 2007 study conducted by Hess et al. concluded that best practice guidelines for the treatment of this population do not exist in schools. Though the need for specialized services is recognized, most interventions used in public schools lack empirical support although public general education placements for these students increased from 44,874 to 304,080 in the last decade (Bruin et al., 2013).

Hess et al. (2007) administered the Autism Treatment Survey to 185 general and special education teachers in Georgia that represented 226 students with ASD from pre-school to twelfth grade. They found that the top five strategies used in schools (i.e., gentle teaching, sensory integration therapy, CBT modifications, assistive technology, and Social Stories™) lack rigorous scientific evidence for use with students with ASD. More specifically, based on Simpson et al. (2005), fewer than 10% of reported strategies were scientifically-based, over one-third of interventions had only limited support (e.g., art therapy), 4.70% of teachers used treatments that are not recommended (e.g., facilitated communication). Also, approximately 40% of interventions were not even mentioned in Simpson et al.’s original 2005 article. This suggests the use of strategies not

yet validated (Hess et al., 2007). Similarly, after surveying educational programs in California, Stahmer et al. (2005) also found that non-researched practices were used because of the lack of training and preparation for teachers and paraprofessionals.

Furthermore, evidence-based interventions for individuals with autism, such as Applied Behavior Analysis (ABA), rely on external agents (e.g., parents, teachers) to administer the treatment. However, with the goal of intervention to increase independence and quality of life, research suggests that these individuals need to learn self-management skills to regulate their behaviors/emotions—of which has already been shown possible for persons with intellectual or mild disabilities (Taylor et al., 2005). In this way, generalization and maintenance of skills are increased as the person can use such skills in multiple settings, provide/receive immediate self-reinforcement, and apply said strategies to both overt and covert behaviors (Singh et al., 2011a). Applied behavior analysts have also historically been reluctant to address anxiety as a cause of problem behavior(s), like aggression, as the emotional state occurs “within the skin”, or is often not directly observable or measurable (Harvey, Luiselli & Wong, 2009) Therefore, behaviorists may often lack anxiety-sensitive approaches which can exacerbate related behaviors.

Overall, empirically supported mental health treatments for youth with ASD are limited, as even approaches with modest efficacy lack consistency in publication, outcome, and dissemination, and often fail to generalize outside a research or clinic setting. Though various anxiety-based protocols and evidence-based treatments, like CBT, exist for neurotypical youth, these approaches may not prove as or at all effective for those with autism due to their unique limitations and functioning. Specifically,

barriers for this population include limited social, linguistic, cognitive, attentional, and adaptive skills and abilities, high comorbidity with disruptive behavior disorders, RRBs and interests, and lack of insight (Selles & Storch, 2013).

However, a 2013 meta-analysis by Selles and Storch noted that while psychotherapeutic studies have varied in their use of unique treatment modifications for youth with anxiety and autism, all approaches are rooted in CBT as developed for neurotypical individuals. For typically developing youth, CBT is the “gold-standard” approach for anxiety disorders. It evidences treatment efficacy, long-term skill maintenance and generalization, and low risk of adverse side effects. CBT uses tactics like exposure and response prevention (E/RP) and inclusion of caregivers in treatment, as these were deemed key components for optimal treatment response in youth. Though slightly varied depending on the particular disorder, CBT for anxiety aims to reduce or eliminate symptoms like excessive worry and/or avoidance behavior(s) via providing psycho-education about anxiety symptoms, identifying triggers, directly challenging and restructuring unhelpful and distorted beliefs through Socratic dialogue and validity testing, using desensitization methods like E/RP, and improving coping skills like self-soothing behaviors to manage anxiety (Selles & Storch, 2013; Szkodny et al., 2014).

Improvements are then a result of extinction learning, the cornerstone of inhibitory learning theory, in which fear associated with neutral stimuli deepened via classical conditioning is left intact as novel, secondary associations develop that evidence the once feared, but neutral, stimulus is, in fact, not harmful (Craske et al., 2014). Sofronoff et al. (2005) also showed that, particularly for youth with ASD, caregiver inclusion is significantly more effective than child-only treatment as caregivers are taught

how to facilitate treatment techniques and goals at-home and reduce anxiety accommodation—thus reducing barriers to treatment, behavior dysregulation and lack of insight in the affected youth (Storch et al., 2009). CBT is assumed to be an effective treatment for anxious youth with ASD due to the similarities in information processing seen between this population and neurotypical anxious youth. Specifically, central coherence theory posits that those with ASD are “over-selective” during information processing, focusing on small, rather than global, contextual details. Similarly, anxious, but typically developing, persons selectively attend to stimuli perceived as fearful or threatening, thus resulting in misinterpretations of ambiguous stimuli and a failure to assess broader contexts (Chalfant et al., 2007).

In four randomized control trials (RCTs) completed between 2005 and 2012, CBT showed significant reductions in anxiety symptoms for youth with ASD comparable to typically developing youth (Chalfant et al., 2007; Reaven et al., 2012; Sofronoff et al., 2005; Wood et al., 2009). Chalfant et al. (2007) found that, of 47 children between the ages of eight and 13 years-old diagnosed with either HFA or AS (i.e., intellectual functioning ranging between low average and superior) and either GAD, social anxiety disorder, SP, or panic disorder, 71.4% of those who received a 16-week family-based CBT intervention no longer met criteria for an anxiety disorder according to DSM-IV at post-treatment. Those in the CBT condition were also reported by teachers and parents to have shown reductions in disruptive behaviors (Chalfant et al., 2007). Likewise, Wood et al. (2009) studied 40 children aged seven to 11 years-old with a diagnosis of OCD, SP, or separation anxiety disorder and ASD, AS or PDD-NOS (i.e., verbal IQ over 70) using a version of the *Building Confidence CBT* program (Wood & McLeod, 2008). The

intervention had an emphasis on behavioral experimentation, parental inclusion, and school consultation. At school, participants were provided social coaching and peer “buddy” and mentoring programs, and these techniques were taught across two sessions to participating teachers and aids. Overall, 78.5% of the experimental group was shown to meet positive treatment response criteria on the Clinical Global Impressions-Improvement Scale, as compared to 8.7% of waitlist participants. Treatment gains were maintained at follow-up, with 80% of CBT participants free of an anxiety diagnosis after three months. Sofronoff et al. (2005) also showed a brief six-week CBT program to be helpful for children with AS, as both the child-only and child-and-parent conditions demonstrated significant decreases in anxiety symptoms on the Spence Child Anxiety Scale-Parent (SCAS-P) compared to a waitlist control. Participants in the child-and-parent condition showed the greatest reductions at six-week follow-up. Overall, to date, seven RCTs showed that CBT was superior to both the wait list and the treatment-as-usual (TAU) in reducing anxiety disorders and symptoms in youth with autism, with the majority of effect sizes greater than .80 (Chalfant et al. 2007; McNally et al. 2013; Reaven et al. 2012; Storch et al. 2013; Wood et al. 2009; Reaven et al. 2009; Sofronoff et al. 2005).

It should be noted that each study implemented ASD-specific modifications to treatment. These included: (a) more visual and structured material, (b) emphasizing receptive rather than expressive skills and abilities (e.g., choosing pre-written thoughts/emotions from a choice board rather than expressing them), (c) having a stronger behavioral emphasis (e.g., reward systems), (d) using simplified and concrete language and cognitive components, (e) integrating the child’s restricted interests to

enhance therapeutic rapport, and (f) using methods to reduce perseverative interests later on (Wood et al., 2009; Chalfant et al., 2007).

Limitations of Current Research

Though modest, the extant literature on CBT for youth with anxiety and autism has many limitations hindering outcome generalization and efficacious implementation. Firstly, all studies yielded small sample sizes, with none exceeding 80 participants, and only a few studies compared CBT to an active control group. Therefore, external validity is highly limited. Additionally, methodological rigor is also impacted as many studies failed to measure treatment integrity. To date, only a few studies implemented appropriate anxiety assessment (i.e., used measures validated for ASD) and assessed related functional outcomes. Relevant literature lacks systematic replication and many aspects of treatment, such as beneficial modifications, remain unexamined. Studies lack identification of key treatment components and identification of predictors, moderators, mediators, and youth characteristics associated with therapeutic success and unsuccess, do not assess level of skill generalization or long-term maintenance, and have only studied youth with HFA or AS (Selles & Storch, 2013; Vasa et al., 2014; Chalfant et al., 2007, Wood et al., 2009). For these reasons, CBT as a treatment for anxiety in youth with autism is not yet considered an “evidence-based practice in psychology” (EBPP) by the American Psychological Association’s (APA) Presidential Task Force on Evidence-Based Psychology, the Society of Clinical Psychology, Division 12. EBPP is defined as “the integration of best available research with clinical expertise in the context of patient characteristics, culture, and preferences” and “...encompasses a broader range of clinical activities (e.g., psychological assessment, case formulation, therapy relationships).” With

the aforementioned lack of knowledge, CBT as a treatment for anxiety in youth with autism is categorized as an “empirically supported treatment” (EST), defined as, “...specific psychological treatments shown to be efficacious in controlled clinical trials...” (APA Presidential Task Force on Evidence-Based Practice, 2006).

Current Study

Wolf and Goldfried (2014) explained that “...in order for [a] field to move from an EST to an evidence-based treatment that works well in practice settings, we need to know more about the clinical experiences of therapists who make use of these supported interventions in actual clinical practice.” They argued that by identifying obstacles to successful treatment faced by every-day clinicians, steps could be taken through research and dissemination to overcome those limitations. Dissemination of effective treatments is defined as, “the targeted distribution of information and intervention materials to a specific public health or clinical practice audience. The intent is to spread knowledge and the associated evidence-based interventions.” The goals of dissemination are the following: (1) increase the “reach” and availability of information, (2) increase consumer motivation to use and implement evidence, and (3) increase consumer’s ability to apply evidence (Methods Guide for Effectiveness and Comparative Effectiveness Reviews, 2014). To do so, disseminating new information requires the identification and participation of the “multiple stakeholders” (e.g., service providers, researchers, students/trainees in relevant fields) responsible for the implementation of research findings. Said stakeholders should work within multiple settings and disciplines as each offers a unique perspective on the obstacles in developing evidence-based practice and can aid in “bridging the gap” between research and practice (Bridging Work Group,

2005). This “bridging” is critical for the study of ESTs for the treatment of anxiety in youth with autism as future research needs to be focused on treatment that acknowledges the unique barriers associated with treating this condition in this population. Until such literature exists, clinicians may remain skeptical of the utility of research findings, unaware of appropriate treatment, hesitant to adhere to treatment fidelity, and unable to disseminate evidence if they perceive it as in- or minimally effective. Thus, in turn, clinicians may encourage dissemination of inadequate treatment.

This gap between research and practice reflects clinician-frustration regarding the limited generalizability of findings produced in controlled research settings—rendering research-based treatments less effective once the various confounds of daily practice are introduced (e.g., psychiatric comorbidities, more severe presentations, family dynamics, resource restraints). Therefore, RCTs might not offer all the information clinicians need to know for successful intervention, and resentment builds in practitioners who feel that, “... the standards and methods of clinical therapy [are] set by those who do the least amount of clinical practice” (Goldfried et al., 2014). While RCTs are essential, other sources of information such as research on client characteristics and preferences, and clinical expertise are needed for EBPP. As such, it is equally essential for clinical practice to inform research as it is for research to inform clinical practice.

A study by Eubanks-Carter et al. (2010) that compiled clinical feedback on how therapists handled parent-patient conflict was noted by researchers to be beneficial via its’ ability to identify factors that hinder the implementation of ESTs. Clinician feedback has shown to provide important hypotheses for future research and identify valuable information that can enhance clinical effectiveness (Goldfried et al., 2014). Such

feedback motivates the design of research studies that reflect practical and realistic clinical scenarios, highlighting population variables not represented in clinical trials, and offering practitioners a more flexible, and overall efficacious, evidence base. Subsequently, the goals of dissemination are then more easily satisfied—i.e., clinicians will be better able to apply findings, thus resulting in increased motivation to adhere to treatment guidelines and aid in the dissemination of relevant sources (Goldfried et al., 2014; Methods Guide for Effectiveness and Comparative Effectiveness Reviews, 2014). As such, the current study aims to gather feedback from practicing clinicians on their experiences in conducting ESTs, namely CBT, to treat anxiety impairments and disorders in youth with ASD.

Implications of the Current Study

Vasa and Mazurek (2018) stated that treatment studies for anxiety in youth with ASD are lagging, leaving clinicians with no fortified clinical pathways to guide the management of a common and debilitating co-condition. Because clinicians are viewed as a, “rich source of clinically based information and hypotheses that are in need of research”, compiling clinician feedback on their experiences in treating anxiety in this population can serve to “bridge the gap” between research and practice—potentially resulting in the expansion and availability of useful research studies. Research viewed as useful by the clinicians may then result in increased implementation and dissemination of successful treatment protocols for the high percentage of youth with anxiety and ASD. This study may additionally contribute to resolving many of the literatures current limitations, as this feedback may bring to light, and motivate further research on, aspects like moderators, mediators, and key treatment variables important for successful

intervention (Selles & Storch, 2013; Vasa et al., 2014; Chalfant et al., 2007, Wood et al., 2009).

Chapter 3

Research Questions

The current study utilizes an inductive, rather than deductive, exploratory research approach. Meaning, the study will examine relationships among variables and patterns within the data that can be generalized to broader populations of interest, and may contribute to eventual theory development regarding adapted treatment for youth with autism. Since inductive approaches do not have bases in a priori theories, theory-derived hypothesis could not be created for the current study (Woo, O'Boyle & Spector, 2017). Instead, the current study will examine the following research questions:

1. What methods do clinicians use to assess anxiety in youth with ASD?
2. What do clinicians see as common barriers to treatment progress for youth with ASD related to the anxiety itself?
3. What do clinicians see as the common barriers to treatment progress for youth with ASD related to individual client characteristics?
4. What do clinicians see as the common barriers to treatment progress for youth with ASD related to the psychotherapy process?
5. What do clinicians see as the common barriers to treatment progress for youth with ASD uniquely related to CBT?
6. What do clinicians see as the common barriers to treatment progress related to the treatment setting?

Chapter 4

Methods

Participants

A total of 142 participants initiated the survey, though 61 participants did not respond to any questions after providing consent for participation. Therefore, the final sample size included 81 participants of whom answered at least one question beyond providing consent. The final sample was then divided into those that completed the survey (i.e., survey completers) and those that did not (i.e., survey non-completers). Survey completion, as modeled in Szkodny et al. (2014), was defined as answering at least one question on the final page of the survey. As such, “survey completers” included 76 participants (93.82% of the sample) and “survey non-completers” included five participants (6.20% of the sample). The average, minimum, and maximum completion rates for survey completers were all 100%. The average, minimum, and maximum completion rates for survey non-completers were all 88%. Results reported within this study are based solely on survey completers due to survey non-completers omitting the majority of questions regarding barriers to CBT for youth with autism, of which is the aim of this study.

All analyses in this study used an alpha level of $p = .05$.

Demographic Information

Of the 76 completers, 81% were female and 18% were male with a mean age of 22.04 years ($SD = 46.13$). The majority of completers identified as Caucasian (70%), and reported to live and work in the United States (73%), and to live (22%) and work (21%) in New York (see Table 1).

Table 1*Demographics of Survey Completers and Non-Completers*

	Completers
	% (n)
Age	<i>N</i> = 75
	M (SD)
	22.04 (46.13)
	% (n)
Gender	<i>N</i> = 76
Male	18.42 (14)
Female	81.60 (62)
Ethnicity	<i>N</i> = 81
Caucasian/White	92.11 (70)
Black/African-American	5.30 (4)
Hispanic/Latinx	3.95 (3)
South Asian	1.32 (1)
Native or First Nation	2.63 (2)
Pacific Islander	1.32 (1)
Multi-Racial	1.32 (1)
Country of Residence	<i>N</i> = 76
United States	96.05 (73)
Canada	3.95 (3)
Country of Work	<i>N</i> = 76

	Completers
	% (n)
United States	96.05 (73)
Canada	3.95 (3)
State of Residence	<i>N</i> = 76
New York	28.95 (22)
Connecticut	5.30 (4)
Texas	7.90 (6)
Ohio	13.16 (10)
Pennsylvania	2.63 (2)
North Carolina	2.63 (2)
Maine	5.30 (4)
Massachusetts	1.32 (1)
Louisiana	1.32 (1)
Idaho	1.32 (1)
British Columbia	1.32 (1)
Wisconsin	1.32 (1)
Florida	1.32 (1)
Washington	6.60 (5)
Oregon	1.32 (1)
Nova Scotia	2.63 (2)
Vermont	3.95 (3)
Maryland	1.32 (1)

	Completers
	% (n)
California	1.32 (1)
New Hampshire	1.32 (1)
Iowa	5.30 (4)
Washington D.C.	0 (0)
Montana	1.32 (1)
Indiana	1.32 (1)
State of Work	<i>N</i> = 76
New York	27.63 (21)
Connecticut	6.60 (5)
Texas	7.90 (6)
Ohio	13.20 (10)
Pennsylvania	2.63 (2)
North Carolina	2.63 (2)
Maine	3.95 (3)
Massachusetts	1.32 (1)
Louisiana	1.32 (1)
Idaho	1.32 (1)
British Columbia	1.32 (1)
Wisconsin	1.32 (1)
Florida	1.32 (1)
Washington	7.90 (6)

	Completers
	% (n)
Nova Scotia	1.32 (1)
Vermont	3.95 (3)
Maryland	1.32 (1)
California	1.32 (1)
New Hampshire	1.32 (1)
Iowa	5.30 (4)
Montana	1.32 (1)
Indiana	1.32 (1)
Nova Scotia, New Brunswick	1.32 (1)
Maine, Massachusetts	1.32 (1)

Instruments

This survey was designed by the primary author to assess clinical experiences in conducting CBT for youth with anxiety and autism. The general survey methods are described in Goldfried et al. (2014). To develop the current survey, the initial instrument described in Szkodny et al. (2014), which targeted CBT's treatment of GAD in neurotypical youth, was revised to address multiple anxious presentations (e.g., GAD, social anxiety, specific phobia), while retaining the overall structure of the original survey including section headings and item stems. Supplemental section headings and item stems were added by the primary author that focused on the functioning, limitations, and service delivery specific to youth with ASD that may adversely impact CBT.

Additions were based on research literature addressing the presentation(s), impairment(s), and treatment limitations of youth with anxiety and ASD. The survey was developed and revised in close collaboration with a team of two licensed psychologists, one masters-level school psychologist and RBT, and an LBA with expert knowledge of ASD, anxiety, and CBT.

The final survey includes 44 questions addressing demographic variables, methods of anxiety assessment, CBT techniques used to treat anxiety, and barriers related to treatment efficacy for youth with anxiety and autism. Such barriers include: (1) the youths' symptoms and related features, and (2) the youths' beliefs about anxiety, (3) other youth problems and characteristics, (4) the youths' social system, (5) expectations of the youths' social system, and (6) the youths' motivation, (7) limitations of CBT, (8) the therapeutic relationship, and (9) the treatment setting. The following instructions precede these sections:

“For the following prompts, please indicate the variable(s) you have observed in your clinical work using CBT to treat anxiety in youth with autism that has limited successful symptom reduction. If you have no experience using CBT for anxiety in youth with autism, please check, “No experience...” under each prompt.”

Each response item was presented as a checkbox and allowed participants to choose more than one.

Additionally, the survey inquired about the methods used by professionals to gather information on relevant treatments for youth with autism and anxiety, barriers to

finding such information, familiarity with common anxiety curriculums for youth with autism, methods used for progress-monitoring, and level of English proficiency.

Procedure

The general method is described in Goldfried et al. (2014). Mental health and behavioral professionals were recruited to participate in an online survey, via Qualtrics, concerning clinicians' experience(s) using ESTs for youth with anxiety and autism. Requests for participants were emailed by the primary author to, and distributed by, the directors of the following U.S. and Canadian professional organizations: Arizona Association of School Psychologists, Louisiana School Psychology Association, Iowa Psychological Association, New York State Psychology Association—School Psychology Division, District of Columbia Psychological Association, Washington State Psychological Association, South Carolina Association of School Psychologists, Maryland School Psychologist Association, Connecticut Association of School Psychologists, Minnesota School Psychology Association, and the Association of Psychologists of Nova Scotia. The survey was also emailed and distributed to the Association for Behavioral and Cognitive Therapies, and several school psychology, clinical psychology, social work, and mental health counseling graduate programs. Requests were made to several other professional organizations targeting clinical and school psychologists, social workers, mental health counselors, and behavioral professionals (e.g., BCBA's, RBT's), though most were unsuccessful. Requests were also made using the social media platform, Facebook, to public and private groups comprised of school psychologists, clinical psychologists, mental health counselors, social workers, BCBA's, LBAs, RBT's, and behavioral paraprofessionals.

The survey required approximately fifteen to thirty minutes to complete, and responses were collected from November 2020 to February 2021. Survey responses were aggregated across respondents. Due the nature of the online survey, it was possible for non-English speakers to participate. Therefore, participants were also asked to rate their level of English proficiency. All survey completers reported an ability to read “college-level text” in English.

Chapter 5

Results

All results reported in this section were calculated via a chi-square test of independence unless otherwise stated.

Therapist Training and Experience

Type, breadth, and duration of participant training and education is depicted in Table 2. Training in CBT for anxiety in youth with autism was reported as mostly received via graduate school coursework (55.30%), self-directed training via books, journals and videos (47.40%), and from attending workshops (43.42%). Only 10% of completers reported receiving formal training through externship experience, 12% through post-doctoral experience, and 26% through internships. About 67% of completers reported having less than 100 hours of training in CBT for youth with anxiety and autism. Only 3.95% reported having between 3,000-5,000 hours, and 3.95% reported over 5,000 hours of CBT training for autistic youth. Similarly, 76.32% of completers reported having 500 or less hours of training in ABA strategies for youth with autism (see Table 2).

The majority (63.20%) of survey completers reported utilizing a cognitive-behavioral approach, with 14.50% and 13.20% using eclectic/integrative and pure behavioral approaches, respectively. Participants adopting psychoanalytic, purely cognitive, family systems, and other approaches comprised approximately 7% of the completer sample (see Table 3).

While most (61.84%) completers reported “Substantial Knowledge” of autism (see Table 6), only 28.95% reported “Very Good” knowledge of anxiety/anxious

presentations in those with autism (see Table 5). Having “Good” knowledge of anxiety in autistic youth was reported by most completers (32.90%; see Table 3).

Regarding treatment, most completers (38.20%) reported a “Good” perceived ability to treat anxiety in youth with autism, and “Acceptable” and “Poor” treatment abilities were reported by 28.94% and 14.50% of completers, respectively (see Table 3).

Concerning experience using CBT to treat anxiety in autistic youth, 39.50% of completers noted less than five years of related experience, and 23.70% of completers reported to have treated less than 10 autistic youths for anxiety in their career thus far. Approximately 23% of completers reported no experience treating autistic youth for anxiety (see Table 3). Of treated youths, less than 5% were noted to have had an actual diagnosis/classification of anxiety. Twenty-seven percent of completers reported anxiety treatment for autistic youth lasting longer than one year, and one quarter of informants reported treatment lasting between six months to one year. Otherwise, 45% of individuals reported treating less than 10 autistic youths for any problem thus far in their career (other than anxiety) (see Table 3).

Having less than five years of general psychotherapy experience was reported by the highest proportion of completers (30.30%), with 18.42% reporting five to 10 years of psychotherapy experience, and 27.63% endorsing none (see Table 3).

Finally, 49.33% of completers endorsed working in a public school, and a total of 58.66% of completers reported working in some type of school setting (i.e., public, private, alternative). Otherwise, 17.33% reported working in an outpatient treatment center, 13.33% in a private practice, 6.70% in a counseling center, 2.70% in a youth’s home, and 1.33% in a residential facility (see Table 4).

Table 2*Therapist Training and Education*

	Completers
	% (n)
Highest Degree Completed	N = 76
Ph.D. in Clinical Psychology	3.95 (3)
Ph.D. in School Psychology	3.95 (3)
Ph.D. in Counseling Psychology	3.95 (3)
Psy.D. in Clinical Psychology	2.63 (2)
Psy.D. in School Psychology	5.30 (4)
Licensed Psychologist	6.60 (5)
M.A. in Clinical Psychology	3.95 (3)
M.A. in School Psychology	5.30 (4)
M.S. in School Psychology	14.50 (11)
M.A. in Counseling Psychology	1.32 (1)
MSEd in School Psychology	1.32 (1)
Ed.D.	5.30 (4)
LCSW	7.90 (6)
LMHC	1.32 (1)
MSEd	2.63 (2)
MSW	3.95 (3)
LBA	2.63 (2)
BCBA	2.63 (2)

	Completers
	% (<i>n</i>)
BCaBA	1.32 (1)
Graduate Student	1.32 (1)
Specialist in School Psychology	9.21 (7)
B.A. in Psychology	1.32 (1)
Ed.S.	5.30 (4)
LBS	1.32 (1)
Psy.D. in School Psychology and BCBA	1.32 (1)
M.A. in Clinical Psychology, LBA	1.32 (1)
M.S. in School Psychology and BCBA	1.32 (1)
Psy.D. in Clinical Psychology and Ph.D. in ABA	1.32 (1)
Ph.D. in Clinical Psychology and BCBA	1.32 (1)
Board Certification	<i>N</i> = 75
None	96 (72)
American Board of Neuropsychology	1.32 (1)
Board Certification in Special Education	1.32 (1)
CBT Training for Anxiety and Autism	<i>N</i> = 76
No training in this area	18.42 (14)
Graduate School Coursework	55.30 (42)
Practicum Experience	40.90 (31)
Externship Experience	13.20 (10)
Internship Experience	34.21 (26)

	Completers
	% (n)
Self-Directed through use of books, journals, videos	47.40 (36)
Attending Workshops	43.42 (33)
Post-Doctoral Experience	15.90 (12)
Peer Supervision	17.11 (13)
Work Experience	3.95 (3)
Undergraduate College Coursework	1.32 (1)
Clinical Supervision	1.32 (1)
<hr/>	
ABA Training for Youth with Autism	<i>N</i> = 76
<hr/>	
No training in this area	31.60 (24)
Undergraduate College Coursework	10.53 (8)
Graduate School Coursework	46.10 (35)
Practicum Experience	27.63 (21)
Externship Experience	6.60 (5)
Internship Experience	21.05 (16)
Self-Directed through use of books, journals, videos	26.31 (20)
Attending Workshops	32.90 (25)
Post-Doctoral Experience	7.90 (6)
Peer Supervision	13.20 (10)
Online Training Certification Course	13.20 (10)
Non-Academic Work Experience	15.90 (12)
<hr/>	
Number of Training Hours in CBT for Anxiety and Autism	<i>N</i> = 76
<hr/>	

	Completers
	% (n)
No experience in this area	0 (0)
Less than 100	67.11 (51)
Between 100-500	17.11 (13)
Between 500-1,000	1.32 (1)
Between 1,000-3,000	5.30 (4)
Between 3,000-5,000	3.95 (3)
Over 5,000	3.95 (3)
Number of Training Hours in ABA for Youth with Autism	
	<i>N</i> = 76
500 or less	76.32 (58)
500-1,000	3.95 (3)
1,000-3,000	5.30 (4)
3,000-5,000	6.60 (5)
Over 5,000	7.90 (6)

Table 3*Therapist Characteristics*

	Completers
	% (n)
Theoretical Orientation	N = 76
Cognitive-Behavioral	63.20 (48)
Eclectic/Integrative	14.50 (11)
Behavioral	13.20 (10)
Psychoanalytic	1.32 (1)
Cognitive	2.63 (2)
Interpersonal Neurobiology	1.32 (1)
Behavioral, Ecological	1.32 (1)
Neuropsychological	1.32 (1)
Family Systems	1.32 (1)
Ability to Intervene with Youth with Autism for Problems	N = 76
Other than Anxiety	
Very Good	26.32 (20)
Good	30.30 (23)
Acceptable	36.84 (28)
Poor	2.63 (2)
Very Poor	3.95 (3)
Knowledge of Anxiety in Autism	N = 76
Very Good	28.95 (22)

Good	32.90 (25)
Acceptable	27.63 (21)
Poor	10.53 (8)
<hr/>	
Ability to Treat Anxiety in Autism	<i>N</i> = 75
<hr/>	
Very Good	17.33 (13)
Good	38.20 (29)
Acceptable	28.94 (22)
Poor	14.50 (11)
<hr/>	
Knowledge of Autism	<i>N</i> = 76
<hr/>	
Some Knowledge	25.00 (19)
Substantial Knowledge	61.84 (47)
Expert Knowledge	13.20 (10)
<hr/>	

Table 4*Therapist Experience*

	Completers
	% (<i>n</i>)
<hr/>	
Current Practice Setting	<i>N</i> = 75
<hr/>	
Public School-General Education	13.33 (10)
Public School-Special Education	36.00 (27)
Special Education/Alternate School	8.00 (6)
Private Practice	13.33 (10)
Outpatient Treatment Center	17.33 (13)

	Completers
	% (n)
Counseling Center	6.70 (5)
Private School	1.33 (1)
Residential Facility	1.33 (1)
Youth's Home	2.70 (2)
Weekly Client Contact Hours	<i>N</i> = 76
Less than 10 hours	39.50 (30)
10 to 20 hours	21.10 (16)
21 to 30 hours	17.11 (13)
Over 30 hours	9.21 (7)
None	13.20 (10)
Psychotherapy Experience	<i>N</i> = 76
Less than 5 years	30.30 (23)
5 to 10 years	18.42 (14)
11 to 15 years	9.21 (7)
16 to 20 years	3.95 (3)
21 to 30 hours	5.30 (4)
31 to 40 hours	1.32 (1)
Over 40 years	1.32 (1)
None	27.63 (21)
Experience Using CBT for Youth with Anxiety and Autism	<i>N</i> = 76
Less than 5 years	39.50 (30)

	Completers
	% (n)
5 to 10 years	21.10 (16)
11 to 15 years	1.90 (6)
16 to 20 years	5.30 (4)
21 to 30 years	2.63 (2)
None	23.70 (18)
<hr/>	
Experience Using ABA for Youth with Autism for	<i>N</i> = 76
Problems Other than Anxiety	
<hr/>	
Less than 5 years	31.60 (24)
5 to 10 years	19.74 (15)
11 to 15 years	6.60 (5)
16 to 20 years	3.95 (3)
31 to 40 years	1.32 (1)
Over 40 years	1.32 (1)
None	35.53 (27)
<hr/>	
Number of Youths with Autism Treated for Anxiety	<i>N</i> = 76
<hr/>	
Less than 10	23.70 (18)
10 to 30	9.21 (7)
31 to 50	7.90 (6)
51 to 70	17.11 (13)
71 to 100	14.50 (11)
Over 100	10.53 (8)

	Completers
	% (n)
None	17.11 (13)
Number of Youth with Autism Diagnosed/Classified with Anxiety	
<i>N</i> = 76	
Less than 5%	23.70 (18)
6 to 15%	9.21 (7)
16 to 30%	7.90 (6)
31 to 50%	17.11 (13)
51 to 75%	14.50 (11)
76 to 100%	10.53 (8)
None	17.11 (13)
Number of Youths with Autism Treated with CBT for Problems Other than Anxiety	
<i>N</i> = 75	
Less than 10	45.33 (34)
10 to 30	14.50 (11)
31 to 50	4 (3)
51 to 70	5.33 (4)
71 to 100	2.70 (2)
Over 100	4.00 (3)
None	24.00 (18)
Typical Length of Anxiety Treatment for Youth with Autism	
<i>N</i> = 76	

	Completers
	% (n)
Less than 3 months	7.90 (6)
3 to 6 months	17.11 (13)
6 months to 1 year	25.00 (19)
Over 1 year	27.63 (21)
No experience in this area	22.40 (17)

Assessment and Treatment of Anxiety

Methods used to assess and treat anxiety in youth with autism are depicted in Table 10. Observation of the youth was reported by completers as the most frequently utilized assessment method (80.30%). Other methods frequently endorsed were records review (76.32%), self-report measures using broad band behavior rating scales (e.g., BASC-3; 68.42%), structured/semi-structured interview (57.90%), and unstructured or informal interview (52.63%). Less than half of completers endorsed employing self-report measures using narrow band anxiety scales (e.g., MASC-2; 33; 43.42%). Anxiety assessment utilizing clinician-administered instruments (e.g., ADIS; 11.84%), scales validated specifically for use with autistic youth (e.g., ASC-ASD; 4.50%), and physiological assessment (2.63%) were the least frequently endorsed strategies (see Table 10).

Also shown in Table 10 are the reported frequencies for methods used in determining the effectiveness of an anxiety treatment for youth with autism. Similar to assessment, the majority of the sample (67.11%) reported using informal observation

during sessions to determine progress. Observing the youth outside of sessions was endorsed by 36.84% of completers. The use of progress-monitoring scales (60.52%) and semi-structured interviews with both the youth and the youth's family (44.74%; 44.74%) were also endorsed as frequently used to determine intervention efficacy.

Table 5*Assessment Methods for Anxiety in Youth with Autism*

	Completers
	% (n)
	<i>N</i> = 76
No experience assessing anxiety in youth with autism	7.90 (6)
Self-report using broad band behavior rating scales (e.g., BASC-3)	68.42 (52)
Self-report using narrow band anxiety scale (e.g., MASC-2)	43.42 (33)
Records Review	76.32 (58)
Observation	80.30 (61)
Structured/semi-structured interview	57.90 (44)
Unstructured or informal interview	52.63 (40)
Clinician administered measures (e.g., ADIS)	11.84 (9)
Clinician administered measures specifically validated for youth with autism (e.g., ASC-ASD)	14.50 (11)
Physiological Assessment	2.63 (2)
Method for Determining Effectiveness of Treatment Program	<i>N</i> = 76
Informal observation during session(s)	67.11 (51)
Informal observation outside of session(s)	36.84 (28)
Progress-monitoring scales	60.52 (46)
Semi-structured interview with youth	44.74 (34)
Semi-structured interview with youth's family	44.74 (34)
Homework review	18.42 (14)

Table 11 shows the commonality of different techniques used in CBT for anxiety in youth with autism. Overall, 71.10% of completers reported using both cognitive and behavioral techniques, and 22.40% endorsed using only behavioral strategies. Individual therapy was the most common modality reported by completers (55.30%). The highest proportion of completers reported utilizing identification of the youth's anxiety triggers (64.50%), identification of negative thoughts, physical sensations, and emotions (60.53%), cognitive restructuring (52.63%), breathing retraining (51.32%), relaxation training (47.40%), psychoeducation (46.10%), and parent training (44.74%; see Table 11).

A moderate amount of completers also reported having the youth's family monitor the youth's anxious behavior(s) outside of session (36.84%), having the youth monitor their own anxious behavior (31.60%), focusing on in-session indicators of anxiety (31.60%), assigning cognitive homework (31.60%), having the client's teacher monitor the youth's anxious behavior(s) (30.30%), and implementing ABA procedures like shaping, task analysis, and natural environment teaching in-session (30.30%; see Table 11).

Less than 30% of completers endorsed utilizing creative supplements for youth expression in-session (e.g., writing, drawing; 28.95%), feedback from others about the youth's anxiety (27.63%), stimulus control for worry (27.63%), out-of-session behavioral exposures (27.63%), identification and targeting of the intolerance of uncertainty (27.63%), motivational interviewing (22.40%), and functional communication training (21.10%; see Table 11).

Among the least frequently reported techniques employed during CBT for anxiety in youth with autism were reported as in-vivo exposures (14.50%), imaginal exposures (14.50%), contingency management (14.50%), values identification (5.30%), and the use of only cognitive interventions (3.95%; see Table 11).

Table 6

Techniques Used in Conducting CBT for Anxiety in Youth with Autism

	Completers
	% (n)
	N = 76
No experience treating anxiety in youth with autism	22.40 (17)
Only behavioral techniques	3.95 (3)
Only cognitive techniques	0 (0)
Both behavioral and cognitive techniques	71.10 (54)
Individual therapy	55.30 (42)
Group therapy	28.94 (22)
Psychoeducation about the nature of worry	46.10 (35)
Identifying anxiety and worry triggers	64.50 (49)
Identifying negative thoughts, physical sensations and/or emotions in response to worrisome situations	60.53 (46)
Cognitive restructuring of negative/distorted beliefs	52.63 (40)
Identifying and directly addressing intolerance of uncertainty	27.63 (21)
Having the client monitor worry and its outcome	26.32 (20)
Having the client monitor anxious behavior	31.60 (24)

	Completers
	% (n)
Having the client's family monitor anxious behavior	36.84 (28)
Having the client's teacher(s) monitor anxious behavior	30.30 (23)
Assigning out-of-session cognitive homework	31.60 (24)
Assigning out-of-session behavioral experiments	23.68 (18)
Assigning out-of-session behavioral exposure(s)	27.63 (21)
Identifying and directly addressing positive/superstitious beliefs about worry	23.70 (18)
Relaxation training (e.g., progressive muscle relaxation, applied relaxation training)	47.40 (36)
Identifying and preventing safety behaviors	25.00 (19)
Mindfulness and/or acceptance-based methods	44.74 (34)
Focus on in-session indicators of anxiety as they arise	31.60 (24)
Breathing retraining (e.g., diaphragmatic breathing)	51.32 (39)
Stimulus control for worry (e.g., picking a time and place for worry)	27.63 (21)
In-vivo worry exposure	14.50 (11)
Imaginal worry exposure	14.50 (11)
Narratives	19.74 (15)
Helping clarify what is important to clients (i.e., values clarification)	5.30 (4)
Self-help readings	7.90 (6)

	Completers
	% (n)
Enhancing self-efficacy in place of worry	14.50 (11)
Creative supplements or alternatives (e.g., journal writing, song writing, drawing, painting)	28.95 (22)
Helping the client understand the developmental roots of fears and worries	23.70 (18)
Assertiveness training	19.74 (15)
Imagery/visualization training	23.70 (18)
Motivational interviewing/enhancement	22.40 (17)
Functional communication training	21.10 (16)
Contingency management	14.50 (11)
Parent training	44.74 (34)
Staff training	28.95 (22)
ABA procedures (e.g., shaping, task analysis, natural environment teaching)	30.30 (23)
Resolution of worrisome conflicts	6.60 (5)
Self-control desensitization (i.e., having client hold onto worry trigger or worry outcome image while using relaxation to cope)	5.30 (4)
Using feedback from others about the clients' anxiety	27.63 (21)

Obstacles to Treatment Efficacy

Limitations to Treatment Progress Related to Anxiety

Table 12 depicts reported frequencies of perceived barriers to CBT for anxiety in autistic youth related to the anxiety. Regarding anxiety symptoms and associated features, severity of the anxiety (44.73%) and subsequent functional impairment (44.73%) were the most frequently reported barriers. Other common barriers were reported as the youth's attentional or information-processing bias towards negative information (39.50%), chronicity of anxiety (34.21%), and anxiety attacks (32.90%). Similarly, 23.70% and 18.42% of completers noted panic attacks and tics, respectively, as common obstacles. About 18% of completers reported clinician difficulty in recognizing/diagnosing/treating anxiety symptoms in this population as an impediment (see Table 12).

The two most common maladaptive youth beliefs reported to interfere with treatment are that his/her/their problems are due to external factors (60.52%), and that his/her/their fears and worries are realistic (53.94%). Youth beliefs about anxiety being an unchangeable part of his/her/their personality were reported by 22.40% of completers, and approximately 48.74% of completers endorsed therapy being impacted by the youth's positive perception of anxiety's functionality (e.g., worry helps the youth prepare for the worst). Beliefs that anxiety is abnormal or dangerous, or that reducing anxiety will have a negative impact on interpersonal relationships, were least frequently reported as obstructive to treatment (6.60%; 6.60%; see Table 12).

Table 7*Perceived Barriers to Treatment Progress Related to Anxiety*

	Completers
	% (n)
<hr/>	
Anxious Symptoms and Associated Features	N = 76
<hr/>	
No experience treating anxiety in youth with autism	18.42 (14)
Chronicity	34.21 (26)
Severity	44.73 (34)
Functional impairment (e.g., travel, work, school, social)	44.73 (34)
Attentional or information-processing bias toward negative information	39.50 (30)
Panic attacks	23.70 (18)
Anxiety attacks	32.90 (25)
Tics	18.42 (14)
Clinician difficulty with differentially recognizing/diagnosing/treating anxiety symptoms	18.42 (14)
None of the above	17.10 (13)
<hr/>	
Youth Beliefs About Anxiety	N = 76
<hr/>	
No experience treating anxiety in youth with autism	17.10 (13)
Fears and worries are realistic	53.94 (41)
Being generally anxious is part of the client's personality and unchangeable	22.40 (17)
Problems are due to external factors (e.g., situation, other people)	60.52 (46)

	Completers
	% (n)
Worry helps the client prepare for the worst	15.80 (12)
Worry actually prevents bad things from happening	13.20 (10)
Worry helps the client to be motivated to get things done	11.84 (9)
Worry helps the client solve problems	7.90 (6)
Being generally anxious is abnormal/dangerous	6.60 (5)
Anxiety is biologically based	11.84 (9)
Loss of vigilance/anxiety will have a negative impact on relationship(s)	6.60 (5)
None of the above	17.11 (13)

Limitations to Treatment Progress Related to Individual Client Characteristics

Perceived barriers to CBT for anxiety in youth with autism related to the youth are depicted in Table 13. High proportions of completers reported that the youth's defiant/disruptive behavior(s) (71.05%), limited interpersonal/social skills (60.52%), cognitive inflexibility (50%), inability to identify emotions (48.70%), limited intellectual/cognitive functioning (48.70%), limited perspective-taking skills (46.10%), behavioral rigidity (44.74%), and resistance to the directiveness of treatment (e.g., homework refusal; 42.11%) were the most common barriers to symptom improvement (see Table 13).

Moderate proportions of completers also endorsed the following youth characteristics as hindrances to efficacious treatment: (a) youth's chaotic lifestyle

(39.50%), (b) perfectionistic/obsessive style (39.50%), (c) inability to identify automatic thoughts (39.50%), (d) limited executive functioning (38.20%), (e) inability to work independently between sessions (38.20%), (f) trauma history (34.21%), and (g) depressed mood/mood disorder (31.60%). Almost one-third of completers also believe that the youth's limited communicative ability impacts therapy (28.95%), while a small proportion of participants reported the youth's unwillingness to give-up safety behaviors (21.10%), low self-esteem (25%), problems with medication (e.g., insufficient dosage; 22.40%), low socio-economic status (27.63%), and inconsistent attendance (26.31%) as treatment barriers. Among the least frequently reported youth problems were physical problems (11.84%), substance abuse (7.90%), and comorbid psychotic disorder (3.95%; see Table 13).

Also depicted in Table 13 is the perceived impact of the autistic youth's social system on treatment progress. Many informants believe that symptom improvement is obstructed due to the following: (a) symptoms being reinforced at-home (56.60%), (b) high stress at-home, school, work, or in social settings (51.32%), (c) high anxiety of family members (48.70%), (d) social isolation of the youth (43.42%), and (e) dysfunction at home, in-school, at-work, or in social situations (43.42%). Approximately one-third of completers believe that the family members' distorted beliefs regarding the youth/youth's impairment and treatment, and the denial of the youth's impairment negatively impact progress (34.21%; 32.90%). Negative treatment impacts due to the family's demand for in-session attention, time constraints, and the loss of a family member/partner/employment were the least frequently endorsed barriers (10.53%; 6.60%; 5.30%; see Table 13).

Table 8*Perceived Barriers to Treatment Progress Related to the Client*

	Completers % (n)
Youth Problems and Characteristics	N = 76
Personality disorders	13.16 (10)
Resistance to directiveness of treatment (e.g., noncompliance with homework)	42.11 (32)
Chaotic lifestyle	39.50 (30)
Inability to work independently between sessions	38.20 (29)
Perfectionistic/obsessive style	39.50 (30)
Premorbid functioning is limited	17.11 (13)
Substance abuse	7.90 (6)
Depressed mood/mood disorder	31.60 (24)
Unwilling to give up safety behaviors	21.10 (16)
Intellectual/cognitive/introspective ability is limited	48.70 (37)
Limited interpersonal/social skills	60.52 (46)
Dependency/unassertiveness	19.74 (15)
Inability to identify automatic thoughts	39.50 (30)
Inability to identify emotions	48.70 (37)
Low self-esteem/self-efficacy	25.00 (19)
Psychotic disorder	3.95 (3)

	Completers
	% (n)
Problems with medication (e.g., insufficient dosage, frequent changes in dosage during treatment)	22.40 (17)
Medication refusal	11.84 (9)
Fear of exposure and associated emotional reactions	14.50 (11)
History of trauma	34.21 (26)
Disruptive/defiant behavior(s)	36.84 (28)
Client expects/requests repeated reassurance	14.50 (11)
History of physical or sexual abuse	14.50 (11)
Low socioeconomic status	27.63 (21)
Physical problems	11.84 (9)
Fear of rejection	13.20 (10)
Diversity issues associated with ethnicity/race/ religion/sexual orientation	15.80 (12)
Limited communication/speech/verbal fluency	28.95 (22)
Avoidance of anxiety triggers	28.95 (22)
Defiance/oppositional defiance	34.21 (26)
Inconsistent attendance	26.31 (20)
Session tardiness	10.52 (8)
Elopement from session	17.11 (13)
Limited attending/attention span	28.95 (22)
In-session stimulatory behavior(s)	15.80 (12)

	Completers
	% (n)
Verbal aggression	21.10 (16)
Physical aggression	22.40 (17)
Limited/impaired executive functioning	38.20 (29)
Verbal stereotypy	10.53 (8)
Cognitive inflexibility	50.00 (38)
Behavioral rigidity	44.74 (34)
Limited adaptive functioning	27.63 (21)
Limited perspective-taking skills	46.10 (35)
Other psychiatric comorbidities	11.84 (9)
None of the above	1.32 (1)
Client Social System	<i>N</i> = 76
No experience treating anxiety in youth with autism	17.11 (13)
Symptoms/dependency is reinforced/supported	56.60 (43)
Stress is/was exceedingly high at home, school, work, and/or socially	51.32 (39)
Trapped in a dysfunctional home, school, workplace, or social situation	43.42 (33)
Social isolation of client	43.42 (33)
The family's denial of diagnosis/es/impairment(s)	32.90 (25)
The family members are very anxious	48.70 (37)
The family members' distorted beliefs regarding client/disorder/impairment/treatment	34.21 (26)

	Completers
	% (n)
Lack of time due to other commitments	6.60 (5)
The family is controlling and critical	15.90 (12)
The family does not support treatment	19.74 (15)
Loss of family member, partner, employment	5.30 (4)
The family refusing participation/training	15.80 (12)
The family's belief in non-evidence based methods/strategies/plans	23.70 (18)
The family refusing to provide the client medication	15.80 (12)
The family demanding too much in-session attention	10.53 (8)

Limitations to Treatment Progress Related to Psychotherapy Process and Technique

Tables 14 and 15 show the reported frequencies of perceived barriers related to the psychotherapy process and the CBT intervention, respectively. Specifically, barriers are reported as related to the youth's family's treatment expectations, youth motivation, therapeutic relationship, and the CBT intervention, itself.

Approximately 44.74% of completers reported that the family's belief that the therapist will do all the work to improve the youth's symptoms is an impediment to treatment. Approximately one-third of completers also endorsed treatment impact due to families believing that treatment will be brief and easy (35.53%), and that the youth will be free of all anxiety and worry after treatment (31.60%). Similarly, families believing that symptom reduction is not good enough, and that therapy, alone, will not reduce anxiety were also reported to obstruct progress (22.40%; see Table 14).

Regarding the youth, 53.95% of completers endorsed that the youth's lack of motivation at the outset of therapy is a common treatment obstacle. Additionally, informants reported that a decrease in the youth's motivation due to their avoidance of anxiety triggers or the directiveness of treatment is a barrier (22.40%). As such, 23.70% of completers noted premature termination as a common obstacle (see Table 14).

Weaknesses in the therapeutic relationship at the beginning of therapy, and the youth's perception that his/her/their distress is not sufficiently understood by the therapist, were reported as common treatment barriers (23.70%; 23.70%). While 21.10% of completers endorsed that the therapist's frustration with slow, minimal, or lack of progress was a treatment obstacle, only 7.90% reported that negative feelings towards the youth commonly impact therapy. Ruptures in the therapeutic alliance with both the youth (7.90%) and youth's family (9.21%) were least frequently reported to impact progress (see Table 14).

Table 15 reports perceived barriers of the CBT intervention, itself. Most commonly reported to impede treatment for youth with autism was the absence of CBT guidelines for youth with limited language/communication (38.20%) and limited cognitive functioning (38.20%). Similarly, the perceived lack of family involvement in CBT, and the absence of guidelines for youth with limited adaptive skills were also reported as negatively impactful by 32.90% and 31.60% of completers, respectively (see Table 15).

Many completers also believe that the difficulty of simulating anxiety-provoking situations in-session, and the perceived inflexibility of CBT protocols also hinder treatment efficacy (26.32%; 25%). A small proportion of completers endorsed that

treatment is impacted due to a lack of guidelines on dealing with resistance/noncompliance (14.50%), too much between-session homework (11.84%), and too much time spent on psychoeducation (9.21%). Barriers related to CBT that were least frequently reported were a lack of guidelines on how to manage comorbid symptoms (9.21%) or interpersonal loss (3.95%), the limited availability of CBT protocols (10.53%), and that CBT is too directive (2.63%; see Table 15).

Table 9

Perceived Barriers to Treatment Progress Related to the Psychotherapy Process

	Completers
	% (n)
Family Treatment Expectations	N = 76
No experience treating anxiety in youth with autism	15.80 (12)
The therapist will do all the work to make things better	44.74 (34)
Pessimism about therapy (e.g., due to disappointment with past therapy)	26.32 (20)
The client will be free of all anxiety and worry	31.60 (24)
The client will be free of all anxiety, worry, and other psychiatric comorbidities	14.50 (11)
The client needs medication to reduce anxiety and worry	22.40 (17)
Treatment will be brief and easy	35.53 (27)
Symptom reduction is not enough	23.70 (18)
None of the above	10.53 (8)
Client Motivation	N = 76
No experience treating anxiety in youth with autism	17.11 (13)

	Completers
	% (n)
Minimal motivation at the outset	53.95 (41)
Premature termination	23.70 (18)
Motivation decreased as the client attributes gains to medications	7.90 (6)
Motivation decreased as some improvement occurs	23.70 (18)
Motivation decreased as the client better understands the nature and function of worry/anxiety	5.30 (4)
Motivation decreased due to the client's avoidance of anxiety triggers and/or directness of therapy	22.40 (17)
Therapy Relationship Issues	<i>N</i> = 76
No experience treating anxiety in youth with autism	15.80 (12)
Therapeutic alliance with the client not strong enough from the outset	23.70 (18)
Therapeutic alliance with family not strong enough from the outset	18.42 (14)
The client does not feel his/her/their distress is sufficiently understood/validated	23.70 (18)
Therapist's frustration with slow/minimal/lack of symptom reduction	21.10 (16)
Therapist's reluctance to make the client anxious by exposing the client to anxiety-provoking stimuli (i.e., exposures)	21.10 (16)
Therapist's negative feelings toward the client (e.g., frustration, irritation, annoyance)	7.90 (6)
A rupture(s) in the therapeutic alliance with the client	7.90 (6)
A rupture(s) in the therapeutic alliance with the family	9.21 (7)

Table 10*Perceived Barriers to Treatment Progress Related to Limitations of the CBT Intervention*

	Completers
	% (n)
	N = 76
No experience implementing CBT for anxiety in youth with autism	22.40 (17)
Does not deal with comorbid problems/symptoms	9.21 (7)
Insufficient focus on affect tolerance/regulation	21.10 (16)
Simulating anxiety-provoking situations in sessions is difficult	26.32 (20)
Relaxation does not work or causes anxiety	19.74 (15)
Does not involve the family in treatment/limited family participation in treatment	32.90 (25)
Does not deal with interpersonal problems	22.40 (17)
Absence of guidelines for youth with limited cognitive functioning	38.20 (29)
Absence of guidelines for youth with limited language/communication	38.20 (29)
Absence of guidelines for youth with limited adaptive skills	31.60 (24)
Worry and anxiety triggers not evident	7.90 (6)
Absence of guidelines for dealing with resistance/noncompliance	14.50 (11)
Not enough time for client to respond to treatment within the time frame of a CBT manual (if using a manual in regular practice)	13.20 (10)
Strict adherence to CBT protocol doesn't allow flexibility	25.00 (19)
Limited availability of structured CBT protocols	10.53 (8)
Client not sufficiently socialized to the treatment model	11.84 (9)

	Completers
	% (n)
Too much time spent lecturing/on psychoeducation	9.21 (7)
Treatment too directive	2.63 (2)
Does not deal with the fear of interpersonal loss	3.95 (3)
Triggers for worry and anxiety are not linked to the clients' history	6.60 (5)
Too much between-session homework assigned	11.84 (9)
Does not deal with comprehensive or lasting change	5.30 (4)
Current coping skills are not linked to past	5.30 (4)

Limitations to Treatment Progress Related to the Treatment Setting

Table 16 shows reported frequencies regarding the current treatment settings of completers and the perceived barriers associated with each. At the time of data collection, approximately 57% of completers worked in a school setting, with 48.72% in a public school, 7.90% in a special education/alternative school, and 1.32% in a private school. The second most common setting was an outpatient treatment center (17.11%), and then private practice (13.20%). Otherwise, only 10.55% of completers reported working in a counseling center (6.60%), a youth's home (2.63%), or residential facility (1.32%; see Table 16).

School Settings. The most common barriers were reported as time constraints (88.63%) and limited resources (e.g., treatment manuals; 68.20%). A high proportion of completers also noted that limited interaction with the youth's family (47.73%), limited interaction with the youth's psychiatric and/or medical providers (45.50%), limited peer

supervision/consultation (38.64%), limited ability for skill generalization (36.40%), and lack of prioritization (e.g., youth misses session to finish classwork; 36.40%) frequently impact treatment. Premature exposure to anxiety triggers and premature termination were reported as least commonly impacting anxiety interventions for autistic youth in schools (13.40%; 11.40%; see Table 16).

Outpatient Treatment Center/Private Practice/Counseling Center. Time constraints were reported as the most common barrier to effective CBT (60.71%). Half of the completers also endorsed a limited ability for skill generalization as a frequent obstacle (50%). Other common barriers were reported as premature termination (35.71%), and limited peer supervision/consultation (32.14%). Limited interaction with the youth's psychiatric and medical providers (21.43%), limited interaction with the youth's family (17.90%), and limited resources (17.90%) were least frequently perceived as barriers to community treatment (see Table 16).

Residential Facilities/Youth's Home. One-hundred percent of the two-person sample reported that time constraints, limited resources, and a limited ability for skill generalization were the most common barriers in residential/home settings. Fifty percent of the sample also noted limited interaction with the youth's family, and a limited ability for in-vivo exposures as common obstacles (see Table 16).

Table 11*Perceived Barriers to Treatment Progress Related to Treatment Setting*

	Completers % (n)
Current Treatment Setting	N = 76
Public School-General Education	13.20 (10)
Public School-Special Education	35.52 (27)
Special Education/Alternative School	7.90 (6)
Private Practice	13.20 (10)
Outpatient Treatment Center	17.11 (13)
Counseling Center	6.60 (5)
Private School	1.32 (1)
Residential Facility	1.32 (1)
Youth's Home	2.63 (2)
Barriers Related to Private Practice/Outpatient Center/Counseling Center Settings	N = 28
Time constraints	60.71 (17)
Limited resources (e.g., treatment manuals)	17.90 (5)
Limited peer supervision/consultation	32.14 (9)
Limited interaction with the youth's family	17.90 (5)
Limited interaction with the youth's psychiatric and/or medical providers	21.43 (6)
Limited interaction with the youth's school	28.60 (8)

	Completers
	% (<i>n</i>)
Inconsistent attendance/punctuality	28.60 (8)
Limited ability for skill generalization	50.00 (14)
Limited ability for in-vivo exposure(s)	35.71 (10)
Premature termination/drop-out	35.71 (10)
Barriers Related to School Settings	<i>N</i> = 44
Time constraints	88.63 (39)
Limited resources (e.g., treatment manuals)	68.20 (30)
Limited peer supervision/consultation	38.64 (17)
Limited interaction with youth's family	47.73 (21)
Limited interaction with the youth's psychiatric and/or medical providers	45.50 (20)
Administrative restraints (e.g., services non-permissible)	31.82 (14)
Lack of prioritization (e.g., client misses session to finish classwork)	36.40 (16)
Inconsistent attendance/punctuality	31.82 (14)
Limited ability for skill generalization	36.40 (16)
Limited ability for in-vivo exposure(s)	27.30 (12)
Constant/premature exposure to school-based anxiety trigger(s) flooding the student	13.40 (6)
Premature termination/drop-out	11.40 (5)
Barriers Related to Residential Facilities and Youth's Home	<i>N</i> = 2
Limited interaction with youth's family	50.00 (1)

	Completers
	% (n)
Limited ability for in-vivo exposure(s)	50.00 (1)
Time constraints	100.00 (2)
Limited resources (e.g., treatment manuals)	100.00 (2)
Limited ability for skill generalization	100.00 (2)

Limitations to Finding and Using New Treatments for Anxiety in Youth with Autism

Perceived barriers to accessing and implementing empirically-supported anxiety treatments for autistic youth were analyzed as endorsed by survey completers. Overall, 72.40% and 46.10% reported the most frequent barriers to be time and financial constraints, respectively. Lack of available and effective information/treatments were also commonly endorsed as treatment impediments (36.84%; 34.21%).

Analyses were also completed to examine participant familiarity with the following anxiety treatment programs: (1) Behavioral Interventions for Anxiety in Children with Autism (BIAC; Ehrenreich-May et al., 2014), (2) Multimodal Anxiety and Social Skills Intervention (MASSI; White et al., 2010), (3) Interventions for Autistic Avoidance (IAA; Moskowitz et al., 2015), (4) Coping Cat (Kendall et al., 2006), (5) Coping Cat-Modified (Keehn et al., 2013), and (6) Cognitive-Behavioral Strategies for Anxiety and Escape-Autism Spectrum Disorder (CBAE-ASD; Mouzakis et al., 2015). Completers rated their familiarity with each program on a scale from “Not At All Familiar” to “Extremely Familiar”. A one-sample median test was conducted to determine if a significant difference existed between the percent of completers that

reported only “Slight” or no familiarity with a particular treatment program, and those that reported “Moderate” to “Extreme” familiarity.

Ultimately, no significant differences were found concerning the level of familiarity with the Coping Cat (Kendall et al., 2006) or Coping Cat-Modified (Keehn et al., 2013) protocols. However, the proportion of completers that reported no familiarity with the BIAC (Ehrenreich-May et al., 2014; .72) and the MASSI (White et al., 2010; .72) were significantly higher than expected (.50), $p = <.001$.

Results showed that the proportion of completers that reported no familiarity with IAA (Moskowitz et al., 2015; .72) and CBAE-ASD (Mouzakitis et al., 2015; .80) were also significantly higher than expected (.50), $p = <.001$. It is important to note that neither the IAA or CBAE-ASD curriculums are real, and were fabricated by the lead author for the purposes of this study.

Supplementally, a chi-square test of independence found that 23.05% and 29.64% of completers reported having some degree of familiarity with the IAA and CBAE-ASD programs, respectively. Otherwise, the highest proportion of completers noted familiarity with the Coping Cat curriculum (Kendall et al., 2006; 58.20%) and the Coping Cat-Modified curriculum (Keehn et al., 2013; 43.87%).

Treatment Information for Youth with Anxiety and Autism

Chi-square tests of independence were conducted to assess the methods used by completers to find and select treatment programs for youth with anxiety and autism. The majority of completers reported to find treatments via workshops/trainings (73.70%), colleague/supervisor recommendations (60.53%), online search engines (e.g., Google, 60.53%) and academic journals (52.63%). Selecting interventions from clinical

repertoires and professional list-servs were also endorsed by 40.80% and 38.20% of completers, respectively. Only 11.84% reported using social media.

Completers were also asked to rate how much they rely on their clinical judgement when selecting treatments for autistic youth. Completers rated this reliance on a scale from “A Great Deal” to “Never”. A one-sample sign test was used to determine if a significant difference existed between the number of completers that reported using “Somewhat” to “A Great Deal” of clinical judgement, and those that reported to “Never” do so. Overall, the proportion of completers that reported using “Somewhat” to “A Great Deal” of clinical judgement (.99) was significantly higher than expected (.50), $p = <.001$.

Post-Hoc Analyses

To better understand the association between perceived barriers and type of training, survey completers were separated into the following three groups: (1) Group 1 (participants having only ABA experience), (2) Group 2 (participants having only psychotherapy experience), and (3) Group 3 (participants having both ABA and psychotherapy experience). Group membership was based on responses to questions 12 (“How much experience do you have using ABA for youth with autism?”) and 20 (“[Years of] Psychotherapy Experience”). If a completer answered “No training” to question 12, he/she/they were placed in Group 2. If a completer answered “None” to question 20, he/she/they were placed in Group 1. If a completer endorsed any answer except for “No training” to question 12 and “None” to question 20, they were placed in Group 3.

Group 1 vs Group 2 vs Group 3. A Kruskal-Wallis H test was performed to determine if there were significant differences between the three groups on their

perceived knowledge of autism. When comparing via medians, there were no significant differences between any of the three groups ($Mdn = 1.00$), $H(3) = 1.80$, $p = .62$. An independent samples median test was then used to examine if significant differences existed between any two groups, and found no such differences ($Mdn = 1.00$), $p = .25$.

The three groups were then analyzed via a Kruskal Wallis H Test, comparing mean ranks, on their knowledge of anxiety in autism. Significant differences between the groups were not found, $H(2) = 5.50$, $p = .064$. A Mann-Whitney U-Test comparing mean ranks then, however, found a statistically significant difference between Group 2 (psychotherapy experience only; $M = 34.00$) and Group 3 (both psychotherapy and ABA experience; $M = 24.29$), $U = 231.00$, $p = .02$, with Group 2 reporting more knowledge.

Next, a chi-square test of independence compared reported frequencies regarding the type of anxiety assessment used for youth with autism between the three groups. No significant differences were found. All three groups reported that the most common assessments methods used were observation and records reviews. Broad (53.33%) and narrow band (26.70%) self-report measures, unstructured or informal interviews (40%), and clinician administered measures (0%) were least frequently reported to be used by Group 1 (ABA experience only) compared to the other groups. A higher proportion of completers in Group 3 (both psychotherapy and ABA experience) reported to use structured/semi-structured interviews (70.60%) when compared to Group 1 or 2 (only psychotherapy experience), though, compared to these groups, had the smallest proportion of completers reporting use of clinician-administered measures specifically validated for youth with autism (11.80%).

Group 2 vs Group 3. Only participants in Group 2 (only psychotherapy experience) and Group 3 (both ABA and psychotherapy experience) were compared via a chi-square on the level and type of psychotherapy training, therapeutic technique, and perceived treatment barriers related to anxiety, the psychotherapy process, youth, practice setting, and CBT intervention.

Overall, there were no significant differences between the groups on their knowledge of autism, number of training hours in CBT for anxiety in youth with autism, years of psychotherapy experience, current treatment setting, or perceived barriers to treatment related to the anxiety, youth's social system, youth motivation, therapeutic relationship, a school, residential or inpatient setting, or the CBT intervention.

Contrastingly, significant differences between Group 2 and Group 3 were found regarding type of training in CBT for anxiety in youth with autism, CBT techniques, and perceived barriers to treatment related to youth problems and characteristics, family treatment expectations, and private practice/outpatient/counseling centers.

A higher proportion of completers in Group 3 (both psychotherapy and ABA experience) endorsed receiving training in CBT for anxiety in autism via graduate school coursework (70.60%), $X^2(2, N = 34) = 8.83, p = <.01$, externship experience (26.50%), $X^2(2, N = 34) = 7.55, p = <.02$, and internship experience (52.94%), $X^2(2, N = 34) = 9.44, p = <.01$, when compared to Group 2 (only psychotherapy experience).

Compared to those with only psychotherapy experience (Group 2), a higher proportion of those with both psychotherapy and ABA experience (Group 3) noted using both behavioral and cognitive techniques, $X^2(1, N = 34) = 7.70, p = <.01$, functional communication training (35.30%), $X^2(1, N = 34) = 6.71, p = <.01$, staff training

(44.12%), $X^2(1, N = 34) = 5.25, p = <.02$, and ABA procedures (52.94%), $X^2(1, N = 34) = 13.33, p = <.001$, during CBT for autistic youth. Group 3, as compared to Group 2, also more frequently endorsed the youth's disruptive/defiant behavior (55.90%), $X^2(1, N = 34) = 11.82, p = <.001$, elopement from session (26.50%), $X^2(1, N = 34) = 4.11, p = <.04$, and physical aggression (32.40%), $X^2(1, N = 34) = 3.75, p = <.05$, as obstacles to effective CBT. Those in Group 2 were more likely to view the youth's fear of rejection (33.33%), $X^2(1, N = 21) = 9.65, p = <.002$, as a hindrance to treatment when compared to Group 3 (2.94%).

Concerning treatment expectations of the youth's family, pessimism about therapy was more highly endorsed as a barrier by professionals having both psychotherapy and ABA experience (Group 3; 38.24%), $X^2(1, N = 34) = 5.40, p = <.02$, compared to those with only psychotherapy experience (Group 2). Though not significantly different, a higher proportion of Group 3 (64.76%) than Group 2 (38.12%) participants reported working in a school setting, while private practice was a more common treatment setting for those in Group 2 (23.81%) than Group 3 (8.82%).

Chapter 6

Discussion

Cognitive-behavioral therapy (CBT) is an extensively researched, validated and utilized treatment for anxiety in neurotypical populations (Szkodny et al., 2014). Though similar treatments for autistic populations are founded in CBT, such interventions lack similar efficacy, scientific attention, dissemination, generalization, and evidence-based adaptations (Selles & Storch, 2013). Effective intervention is then limited for youth with autism even though anxiety occurs in as many as 84% of autistic persons (White et al., 2009). In an effort to “bridge the gap” between research and practice (Goldfried et al., 2014), the current study aimed to gather clinician feedback on the barriers to conducting CBT for anxiety in youth with autism. It is the hope that such information will influence the creation of research studies targeting such barriers, and yield efficacious adaptations to CBT.

Compared to survey completers, a higher proportion of non-completers reported having no training in, or experience conducting, CBT for youth with anxiety and autism, and to have only “Some Knowledge” of autism compared to “Substantial Knowledge”. Non-completers also reported less hours of weekly client contact compared to completers. Therefore, it is possible that these individuals did not complete the survey due to feeling unqualified to do so. More so, two survey non-completers held a M.A. in school psychology, one held a M.S. in school psychology, one had a Psy.D. in clinical psychology, and one was a licensed clinical social worker. Since over half of non-completers were master-level clinicians, it may be likely that the lesser amount of psychotherapy training, as compared to doctoral-level professionals, impacted their

perceived knowledge of this topic and ability to complete the survey. It seems critical for knowledge of, and training in, mental health treatment to be better disseminated throughout graduate training programs so that clinicians likely to engage in psychotherapy acquire such skills. Limitations of the current study are that findings may not generalize to professionals with only little experience treating anxiety in youth with autism.

The highest proportion of completers held a M.A. in school psychology. Other frequently reported degrees were a license in clinical social work, Psy.D. in school psychology, doctorate (Ph.D. or Psy.D.) in clinical psychology, and license in psychology. Relatedly, 58.66% of completers endorsed working in some type of school setting, with the highest proportion working in a public school (49.33%). Research states that approximately 16% of youth receive mental health services, and 70-80% of those youths access such supports in school (Rones & Hoagwood, 2000). Therefore, it is a positive finding that a high proportion of school-based professionals felt qualified to complete this survey, as it suggests that they have needed experience treating anxiety in youth with autism.

This may also suggest that school-based professionals receive more training and experience in treating autistic populations compared to other mental health providers, and highlights a need for more extensive education and training in autism treatment for other types of professionals. Though the study examined some setting-specific barriers, future research should aim to determine a more expansive list of obstacles, and needed adaptations, for specific treatment settings.

A limitation of this study is that it did not assess which type of professional endorsed specific experience markers or treatment barriers, however, analyses indicated that, on average, participants reported receiving four different types of training experiences focused on treating youth with autism (e.g., internship training, workshop training, post-doctoral training, behavioral training, therapeutic training).

Another limitation of this study is the underrepresentation of professionals from fields other than psychology—especially school psychology. The current sample included small proportions of professionals like mental health counselors and social workers, and future studies should look to include a broader range of professionals likely to provide services to youth with autism.

What methods do clinicians use to assess anxiety in youth with ASD?

The most commonly endorsed methods of anxiety assessment for youth with autism were observation, records review, self-report using broad band behavior rating scales (e.g., BASC-3), structured/semi-structured interview, and unstructured or informal interview. Two of the least commonly endorsed were general clinician-administered measures like diagnostic interview schedules, and clinician-administered measures specifically validated for youth with autism. Observation and progress-monitoring scales were also most commonly endorsed as used to determine treatment effectiveness.

Silverman and Ollendick (2005) stated that observations of anxiety symptoms are most often useful in gathering subjective ratings of youth distress during anxiety-provoking situations, and are helpful in gathering contextual information regarding environmental predictors and mediators. However, in research, observation, alone, is not frequently used to identify and quantify specific anxious symptoms, or judge treatment

outcome (Silverman & Ollendick, 2005). This may be due to the difficulty of differentially assessing/diagnosing anxiety symptoms in the presence of possible comorbidities, and may be especially concerning in autistic populations in which anxiety symptoms may manifest atypically (Selles & Storch, 2013).

Over 50% of the current sample endorsed having only “Acceptable” or “Good” knowledge of anxiety in autism, as compared to “Very Good” knowledge, with the majority (39.50%) of completers having less than five years of experience treating anxiety in this population. Knowing that anxiety manifests atypically in those with autism (Selles & Storch, 2013), it is potentially troublesome for professionals to rely on their personal judgement regarding the presence of anxiety in autistic persons when many reported relatively little experience seeing and treating such presentations. Therefore, the possibility of misdiagnosis, and thus insufficient treatment, increases—exacerbating the limited information currently available on effective treatment in autistic populations.

In addition to the 39.50% of completers having less than five years treating autistic youths, 30.30% have less than five years of general psychotherapy experience, with 48.72% having less than 10 years of experience. Therefore, it seems that the majority of completers are relatively new to psychotherapy—suggesting a possibility of newer professionals being the primary providers for autistic youth. This suggests that older psychotherapists with more experience have less experience treating youth with autism, and this is potentially troublesome since such “veteran” psychotherapists are more likely to be in supervisory positions. Their service modalities then have considerable influence in the training of new clinicians. If not well-versed in autism treatment, dissemination of effective knowledge and therapy is further hindered.

However, the limited sample size of this study may hinder such generalizations, and future research should aim to replicate these findings with a larger sample.

The impact of such dynamics can also be seen in the identification of anxiety treatments for youth with autism. Over half (60.53%) of completers reported finding treatments for youth with autism via colleague/supervisor recommendation. Without those in supervisory roles having current knowledge and training in autism treatment, the training of novel clinicians may be negatively impacted.

Furthermore, other strategies like structured, semi-structured, and unstructured clinical interviews can produce significant error dependent on the informant, and may not yield adequate differential diagnoses (Silverman, 1994). However, interview schedules like the Anxiety and Related Disorders Interview Schedule-Child/Parent Version (ADIS-C/P) have shown the strongest ability to provide reliable and valid diagnoses, and be sensitive to clinical change (Silverman & Ollendick, 2005). Therefore, it may be troublesome that only a low proportion of informants endorsed using such schedules. However, even strong measures like the ADIS-C/P may be compromised due to the atypical symptom presentation found in individuals with autism, as these measures are not normed on this population. Knowing that the likelihood of non-traditional anxious presentations increases with increases in autism severity (Kerns et al., 2014), it is imperative to utilize assessment measures validated specifically for youth with autism. Approximately 23% of completers reported that zero to less than five-percent of autistic youths seen in treatment had an anxiety diagnosis—insufficient assessment methods may provide a rationale for this finding.

What do clinicians see as common barriers to treatment progress for youth with ASD related to the anxiety itself?

The most commonly endorsed barriers were functional impairment and attentional or informational-processing biases towards negative information. The youth believing that his/her/their problems are due to external factors, and that his/her/their fears and worries are realistic were also reported as common obstacles.

Cognitively, those with autism are known to have significant difficulties with central coherence (or “seeing the big picture”), executive functioning, and theory of mind (i.e., perspective-taking and empathizing skills; Belmonte et al., 2004). As a result, autistic individuals are typically hyper-focused on narrow contextual details, lack abstract and flexible thought needed in emotional introspection, identification and articulation, and demonstrate considerable cognitive and behavioral rigidity. Therefore, youth with autism may require a higher degree of flexibility in treatment regarding pacing, scaffolding, and the use of concrete, rather than abstract/Socratic, educational supplements and discussions. Studies by Wood et al. (2009) and Chalfant et al. (2007) have shown early success in utilizing such methods like concrete/simplified language and pre-written choice boards. A high degree of knowledge of autism is then required to effectively recognize, implement, adapt, and monitor the use of such methods. In the current sample, approximately 62% of completers endorsed having “Substantial Knowledge” of autism, of which is a promising finding.

However, only 13.20% of completers reported having “Expert” knowledge of autism—thus suggesting a lack of “experts” in the area of treating youth with autism for anxiety. This finding underscores the importance of proper training during graduate

school programs to foster better dissemination of, and experience in, the treatment of this population.

One of the least common barriers was reported as the clinician's difficulty differentially recognizing/diagnosing/treating anxiety symptoms in autistic youth.

Though this is a positive finding, a limitation of the current study is a lack of assessment of clinician's perceived effectiveness in treating anxiety in youth with autism. It would be important for future studies to examine success rates to determine associations between perceived treatment ability and actual treatment success.

What do clinicians see as the common barriers to treatment progress for youth with ASD related to individual client characteristics?

The following were the most commonly endorsed barriers related to youth problems and characteristics, and the youth's social system: (a) limited interpersonal/social skills, (b) cognitive inflexibility, (c) limited intellectual/cognitive/introspective ability, (d) inability to identify thoughts, (e) limited perspective-taking skills, (f) symptoms/dependency is reinforced at-home, (f) stress is exceedingly high at home, school, work, or in social settings, and (g) family members are very anxious.

Current research on CBT adaptations for persons with intellectual disability discusses the use of the cognitive difficulties framework of distortions and deficiencies (Dagnan & Chadwick, 1997; Beail, 2003; Willner, 2005). Essentially, cognitive-disorder based interventions target identifying and modifying negative automatic thoughts, core themes, and related maladaptive attitudes and beliefs. Cognitive deficit based approaches use more structured behavioral strategies like self-monitoring and self-instructional

training to aid weaknesses in information acquisition and processing. Therefore, cognitive deficit approaches are most commonly used for people with limited cognitive functioning (Surley & Dagnan, 2017). Cognitive distortion work for people with cognitive impairments is often omitted or reduced due to the abstract nature of such work. However, about 52% of completers endorsed using cognitive restructuring for youth with autism. Therefore, future research clearly utilizing and comparing each type of intervention and its efficacy as related to cognitive ability is critical.

Suggested adaptations to CBT for populations with limited cognitive functioning, like those with autism, are those flexible enough to address limitations whilst maintaining treatment fidelity (Surley & Dagnan, 2017). Whittington and Grey (2014) call this “metacompetence”, and define it as the “ability to apply therapy artfully, in a flexible and individually tailored way”, while still adhering to the core principles of CBT. It would be important to examine the CBT training provided in graduate programs as this impacts the clinician’s ability to apply CBT in a masterfully flexible way. Based on results of the current study, it would be especially critical to examine psychotherapy training in master-level programs since related coursework is not as extensive as in doctoral-training programs. Since CBT for autistic youth requires flexibility, ensuring that professionals first master core therapeutic principles is important.

In a meta-analytic review of 23 studies describing CBT adaptations for persons with intellectual disability, Surley & Dagnan (2017) found such “flexible” adaptations to be decreasing the length of sessions, increasing the number of sessions per week or in total, increasing communication with caregivers, allowing breaks in-session, providing direct

assistance to the client in his/her/their daily life, increased consultation with staff and peers, and having the clinician adopt a higher level of patience.

Other adaptations reported as common and effective for this population are the inclusion of caregivers and support staff in-sessions, modifying or adding-in activities (e.g., worksheets), choosing assessment and progress-monitoring measures based on developmental, rather than chronological, age, and adapting language (e.g., using the client's language/interests, concise sentences; Surley & Dagnan, 2017). While approximately 44% of the current sample endorsed including some aspect of parent training in treatment, only about 28% reported utilizing staff training, and about 28% reported using creative alternatives like writing or drawing. Therefore, this suggests trouble in the dissemination of needed information, and future research should aim to replicate these types of studies and make this information more accessible.

To that end, the current study gathered information on the most common sources used to find treatments for anxiety in youth with autism. Most commonly, completers endorsed utilizing workshops/trainings, colleague/supervisor recommendation, online search engines, academic journals, and clinical repertoires. Thus, making studies more freely accessible online (e.g., explicit teaching in how to find information online, making access free-of-charge), and increasing the frequency, narrowing the focus, or reducing the fees of workshops/trainings may increase needed dissemination and impact future practice.

Due to the high percentage of informants that endorsed treatment barriers related to the youth's family/home lifestyle, future research should also aim to assess the impact of caregiver training, given both concurrently along with the youth's treatment and as the primary form of treatment, on youth anxiety symptoms.

What do clinicians see as the common barriers to treatment progress for youth with ASD related to the psychotherapy process and technique?

The most commonly reported barriers were the youth's family's expectation that the therapist will do all the work to improve youth symptoms, that the youth will be rid of all anxiety, and that treatment will be brief and easy. The family's pessimism about treatment, the youth having minimal motivation at the beginning of therapy, and the therapeutic alliance with the youth being weak at the beginning of therapy were also commonly reported impediments.

Such reports underscore the importance of involving caregivers in treatment to provide needed psychoeducation. Concerning motivation, Taylor, Novaco, and Brown (2016) noted implementing a "preparatory phase" into CBT for individuals with intellectual disabilities. In their study, this phase included six sessions aimed at engaging and motivating the client before introducing the twelve-session "treatment phase". Elaboration of specific techniques was unavailable. Additionally, though this study found CBT effective for reducing anger in this population, the impact of this "preparatory phase" was unclear (Taylor, Novaco, & Brown, 2016). However, this phase may be a critical factor in treating youths that do not understand, want, or fear treatment, and may aid rapport building. Future studies should replicate the use of this phase, as well as study variations in the number of sessions, to determine its effectiveness in ameliorating motivational and relationship-based barriers in autistic youth. This research is especially important considering the high percentage of respondents that endorsed barriers relating to the youth's low motivation for treatment and a weak therapeutic alliance. Since these findings may suggest a lack of knowledge or skill in, or, perhaps, desire for, developing a

positive therapeutic rapport with an autistic youth, guidelines regarding such processes are critical.

Surley and Dagnan (2017) discuss the potential positive impact of disability/rehabilitation approaches on client motivation. This requires explicitly discussing the client's disability in treatment to help the client understand their strengths and limitations. Researchers argue that those experiencing societal stigma due to a disability experience negative psychological impact, of which increases their vulnerability to mental health difficulties. Therefore, it is believed that supporting a positive self-view through disability approaches will help foster client motivation and positive treatment outcomes (Surley & Dagnan, 2017; Dagnan & Waring, 2004).

However, such approaches depend on cognitive ability and warrant further study.

What do clinicians see as the common barriers to treatment progress for youth with ASD related to CBT?

The most frequently endorsed obstacles were the absence of guidelines for youth with limited cognitive functioning, communication and adaptive skills, lack of family involvement, and CBT protocols not allowing flexibility. Such reports underscore the importance of the current study in its aim to "bridge the gap" between research and practice. It is imperative for future research to craft studies specifically targeting CBT adaptations for autistic youth, and to determine the efficacy of each.

What do clinicians see as the common barriers to treatment progress related to the treatment setting?

The biggest barriers associated with school settings were time constraints, limited resources (e.g., treatment manuals), limited interaction with the youth's family,

psychiatric and medical providers, limited peer supervision/consultation, and lack of prioritization (e.g., youth misses session to finish classwork). In outpatient centers/private practice/counseling centers, the most common barriers were time constraints, limited ability for skill generalization and in-vivo exposure, premature termination, and limited peer supervision/consultation. Lastly, time constraints, limited resources, and limited ability for skill generalization were the most commonly reported barriers in residential facilities/youth homes.

Time constraints were the most common barrier reported for each type of setting. As such, it would be imperative for future studies to assess modified yet efficacious timelines for anxiety treatment in autistic youth. This is important since it has been suggested that modifying session length and frequency are beneficial when treating these individuals (Surley & Dagnan, 2017). Decreasing the length of individual sessions may aid weaknesses in attentional stamina and processing speed, while increasing the number of sessions per week may ensure more timely progress, and reinforce learning of concepts and skills through repetition and exposure. Knowing the optimal session length for youth with autism may be particularly beneficial for school-based professionals since they typically have less time available for individual sessions. This way, they can assume more confidence in, and plan more effectively for, shorter sessions. It is also critical to understand how much longer treatment for autistic youths takes, in total, as compared to neurotypical individuals. This knowledge may help reduce perceived barriers like time constraints and lack of intervention flexibility if clinicians can prepare for a longer treatment without the pressure of wanting the youth to respond within a “typical” timeframe.

A limited ability for in-vivo exposure and skill generalization were also commonly reported as barriers; possibly due to controlled school and clinical settings lacking replication of real-life anxiety-provoking situations. Multi-component treatment packages may prove exceptionally beneficial for autistic youths. Meaning, for example, receiving psychotherapy services in controlled settings for skill acquisition, and receiving home or community-based coaching for skill rehearsal, repetition, and generalization. Nizamie et al. (2010) found that a multi-component treatment package consisting of psychosocial therapy, physiotherapy, medication consultations, speech therapy, and physical therapy resulted in significant improvements in motor, language, social skill, and adaptive functioning for a two-year-old with autistic regression. While it is common for youth with autism to receive multiple school and home-based services, future research should examine the impact of the inclusion of psychotherapy services on anxiety and overall quality of life.

Overall, each participant reported an average of 33 barriers related to treating anxiety in youth with autism. This high number of perceived barriers highlights the importance of the current study, and the need for future research to create studies specifically targeting the unique modifications needed to treat this population.

Post-Hoc Analyses

Overall, professionals in Group 2 (only psychotherapy experience) more frequently reported working in outpatient centers and private practice than those in Group 1 (only ABA experience) or 3 (both psychotherapy and ABA experience). Those in Group 3 (having both psychotherapy and ABA experience) more frequently reported working in school settings than the other groups. A higher percentage of members in

Group 3, rather than Group 1 or 2, also reported disruptive/defiant behaviors, elopement from session, and physical aggression as barriers to CBT. These differences may suggest that school-based professionals treat autistic youths with higher levels of impairment. Therefore, enhanced creation, replication, and dissemination of studies adapting CBT for autistic youths in schools is critical.

Another target for future research may be to assess whether having both psychotherapy and ABA experience allows clinicians to more easily and accurately identify autism and its related emotional challenges. Future research should gather information on the perceived treatment effectiveness of professionals with different types of psychotherapy and behavioral training to understand what, if any, differences in training impact service delivery.

An unexpected finding was the low endorsement of the “limited availability of structured CBT protocols” as a barrier to effective CBT for autistic youth. This finding was surprising since barriers like “limited guidelines for youth with limited cognitive functioning/adaptive skills/language/perspective-taking skills” were among the most commonly endorsed barriers. “Lack of effective/available information/treatments” was also frequently reported as a barrier to finding treatments for anxiety in youth with autism. This juxtaposition could possibly be due to participant fatigue, or could suggest the use of CBT protocols not validated for youth with autism. As such, future research should assess what anxiety curriculums are currently being used for youth with autism, and the perceived efficacy of each, to better understand the state of current treatment, and lend insight into why certain therapies are successful or unsuccessful.

Limitations

A limitation is the small overall sample size ($N = 81$). It is hypothesized that the small sample size is due to professionals having limited experience treating anxiety in youth with autism, and so felt unqualified to complete the survey. The current sample also only included professionals from the United States, with most from New York, and most participants had a cognitive-behavioral orientation. The majority of the sample were school-based professionals, mostly Caucasian, and those relatively new to psychotherapy. Since these factors limit the external validity of the study, it would be important for this study to be replicated with a larger and more diverse sample. This would gather a greater understanding of the differences in psychotherapy training and technique, knowledge of autism, and therapy experience of current clinicians.

Chapter 7

Implications for the Profession of School Psychology

Findings of the current study, in conjunction with existing research, suggest that school-based professionals are the primary providers of mental health treatment for youth with anxiety and autism (Rones & Hoagwood, 2000). They also suggest that school clinicians may, more so than community-based professionals, serve autistic youths with more severe impairments like defiant, aggressive, and elopement behaviors. It is then imperative for research to disseminate information on effective adaptations to treatment for autistic populations, especially for delivery in school settings. Without such knowledge, these youth may suffer from a lack of adequate treatment, and thus from continued emotional and behavioral difficulties (Kerns et al., 2015).

The current study lends to this body of research by assessing common barriers observed when treating youth with autism for anxiety. Understanding such limitations will allow future studies to more specifically address these obstacles, and examine adaptations for overcoming them—thereby making research-based practices more practical for clinicians to implement. This information will be critical for school psychologists to receive and adopt into their treatment of autistic youth, and disseminate via supervisory roles.

Appendix A Consent Form

Purpose: The following questionnaire is part of a doctoral dissertation study being conducted at the St. John's University Department of Psychology by Michelle Kirkland, M.S., under the supervision of Dr. Raymond DiGiuseppe, Ph.D., ABPP, Professor of Psychology at St. John's University. The current study aims to gain knowledge on the barriers impacting mental health treatment for anxiety for children and adolescents with autism spectrum disorder (ASD). You are being asked to participate in this study due to your experience providing psychiatric, psychological, and/or behavioral treatment to persons with ASD that are 18 years old or younger. This study has been approved by the St. John's University's Institutional Review Board (IRB).

Procedure: As a participant, your participation will take place online. You will be asked to answer questions regarding your perceptions about and experience in providing clinical and/or behavioral services for children and adolescents with ASD. You will also be asked about demographic variables like age, gender, ethnicity, educational level, years of training and experience, etc.

Confidentiality: We want to let you know that your responses will be held in complete confidence. They will not be released to anyone and your identity will be kept entirely anonymous. We will not collect identifiable information from you and will delete any identifiable information that might be provided to us accidentally. Data will be grouped, analyzed and reviewed only by the author under direction of her supervisor. Data will not be linked with names by any means. No personally identifiable information will be included in the analysis of findings.

Participation and Withdrawal: It is your choice to participate in this study. You may withdraw your participation at any time without penalty of any sort. If you come across a question that makes you feel uncomfortable, you do not have to answer it. We anticipate that your participation will take about 15-30 minutes.

Risks and Benefits: There are no physical risks involved in this study. Potential risks include annoyance or fatigue due to questioning. Although you may not receive any direct benefits, this study will help further knowledge and research regarding critical treatment for children and adolescents with ASD.

Questions: If you have any questions or concerns, please contact either Ms. Kirkland at michelle.kirkland16@stjohns.edu or Dr. Raymond DiGiuseppe at digiuser@stjohns.edu or (718) 990-1955. Furthermore, you may also contact the University's Human Subjects Research Review Board and speak to Dr. Marie Nitopi at 718-990-1440 or at nitopim@stjohns.edu.

Thank you for your cooperation.

Appendix B Demographic Information

Thank you in advance for your participation. We believe your responses will be informative and help us understand how to better develop anxiety treatments for youth with autism spectrum disorder (ASD).

For the following questions, the term “youth” refers to children and adolescents aged 18 years old or younger, and “family” refers to the youth’s parent(s)/caregiver(s)/legal guardian(s). “Youth with autism” refers to individuals with an official diagnosis per DSM-IV or DSM-5, and/or classification per IDEA, of autistic disorder (AD), Asperger’s syndrome (AS), pervasive developmental disorder-not otherwise specified (PDD-NOS), ASD, or autism. When describing assessment and treatment, responses should reflect services provided in individual or group formats for one or more of the following presentations treated with or without a formal diagnosis or classification: generalized anxiety disorder, social anxiety disorder, separation anxiety disorder, specific phobia, obsessive-compulsive disorder, posttraumatic stress disorder, acute stress disorder, panic disorder, and/or agoraphobia.

Demographics

1. Age in years: _____
2. Gender:
 - a. Male
 - b. Female
 - c. Transgender male
 - d. Transgender female
 - e. Non-binary
 - f. Gender fluid
3. Ethnicity:
 - Caucasian
 - Black/African American
 - Hispanic/Latinx
 - East Asian American
 - South Asian
 - Native or first Nation
 - Other
 - Please describe: _____
 - More than one ethnicity
 - Please describe: _____
 - Rather not answer
4. In what country do you live?
 - a. United States
 - b. Bermuda
 - c. Bahamas
 - d. Canada
 - e. Australia

- f. Ireland
- g. Hong Kong
- h. New Zealand
- i. South Africa
- j. United Kingdom
- k. Other: _____

5. In what country do you work?

- a. United States
- b. Canada
- c. Australia
- d. Ireland
- e. Hong Kong
- f. New Zealand
- g. South Africa
- h. United Kingdom
- i. Other: _____

6. In what State or Province do you live: _____

7. In what State or Province do you work: _____

Training & Education

Degree(s) Completed

Check all that apply:

- Ph.D. in clinical psychology
- Ph.D. in school psychology
- Ph.D. in counseling psychology
- Ph.D. in educational psychology
- Ph.D. Ph.D. in social work
- Ph.D. in applied behavior analysis (ABA)
- Psy.D. in clinical psychology
- Psy.D. in school psychology
- Psy.D. in counseling psychology
- Psy.D. in ABA
- Licensed psychologist
- M.A. in clinical psychology
- M.A. in counseling psychology
- M.A. in school psychology
- M.A. in ABA
- M.S. in clinical psychology
- M.S. in school psychology
- M.S. in ABA
- MEd in school psychology
- Ed.D.
- DSW

- LCSW
- LMHC
- M.A.
- M.S.
- MSEd
- M.D.
- MSW
- MSc
- LBA
- BCBA
- BCaBA
- RBT
- Paraprofessional
- Graduate student
- Other

Please describe: _____

Do you have any board certifications?

- No
- Yes

If yes, which one(s): _____

How did you receive your training in CBT for youth with anxiety and autism?

Check all that apply:

- No training in this area
- Graduate school course work
- Practicum experience
- Externship experience
- Internship experience
- Self-direct through use of books, journals, videos
- Attending workshops
- Post-doctoral experience
- Peer supervision
- Other

Please describe: _____

Approximately how many hours of training do you have in this area?

- Less than 100
- 100-500
- 500-1,000
- 1,000-3,000
- 3,000-5,000
- Over 5,000

How did you receive your training in ABA for youth with autism?

Check all that apply:

- No training in this area
- Undergraduate college
- Graduate school course work
- Externship experience
- Internship experience
- Self-directed through use of books, journals, videos
- Attending workshops
- Post-doctoral experience
- Internship
- Peer supervision
- Online training and/or certification course
- Other

Please describe: _____

Approximately how many hours of training do you have in this area?

- Less than 100
- 100-500
- 500-1,000
- 1,000-3,000
- 3,000-5,000
- Over 5,000

How would you describe your theoretical orientation to treatment?

- Cognitive
- Behavioral
- Cognitive-Behavioral
- Psychoanalytic
- Psychodynamic
- Experiential/humanistic
- Existential
- Family systems
- Common factors
- Other

Please describe: _____

Please rate your knowledge of ASD:

- 1 (No knowledge)
- 2 (Little knowledge)
- 3 (Some knowledge)
- 4 (Substantial knowledge)
- 5 (Expert knowledge)

Please rate your ability to intervene with youth with ASD for problems other than anxiety:

- 1 (Very poor)
- 2 (Poor)
- 3 (Acceptable)

- 4 (Good)
- 5 (Very good)

Please rate your knowledge of anxiety/anxious presentations in youth with autism:

- 1 (Very poor)
- 2 (Poor)
- 3 (Acceptable)
- 4 (Good)
- 5 (Very good)

Please rate your ability to treat anxiety in youth with autism:

- 1 (Very poor)
- 2 (Poor)
- 3 (Acceptable)
- 4 (Good)
- 5 (Very good)

Therapist Experience

What type of setting do you currently practice in?

Check all that apply:

- Private practice
- Public school-regular education
- Public school-special education
- Private school
- Special education/alternative school
- Outpatient treatment center
- Counseling center
- Inpatient unit
- Residential facility
- Client's home

Current Weekly Client Contact

- None
- Less than 10 hours
- 10 to 20 hours
- 21 to 30 hours
- Over 30 hours

Psychotherapy Experience

- None
- Less than 5 years
- 5 to 10 years
- 11 to 15 years
- 16 to 20 years
- 21 to 30 years

- 31 to 40 years
- Over 40 years

How much experience do you have using CBT for anxiety in youth with autism?

- None
- Less than 5 years
- 5 to 10 years
- 11 to 15 years
- 16 to 20 years
- 21 to 30 years
- 31 to 40 years
- Over 40 years

How much experience do you have using ABA with youth with autism?

- None
- Less than 5 years
- 5 to 10 years
- 11 to 15 years
- 16 to 20 years
- 21 to 30 years
- 31 to 40 years
- Over 40 years

How many youths with autism have you treated for anxiety?

- None
- Less than 10
- 10 to 20
- 21 to 30
- 31 to 40
- 41 to 50
- 51 to 100
- Over 100

Of the youths with autism treated for anxiety, how many had a documented anxiety diagnosis/classification?

- None
- Less than 5%
- 6-15%
- 16-30%
- 31-50%
- 51-75%
- 76-100%

How many youths with autism have you treated for problems other than anxiety?

- None
- Less than 10

- 10 to 20
- 21 to 30
- 31 to 40
- 41 to 50
- 51 to 100
- Over 100

What is the typical length of anxiety treatment for youth with autism?

- No experience treating anxiety in youth with autism
- Less than 3 months
- 3 to 6 months
- 6 months to 1 year
- Over 1 year

Appendix C

Cognitive-Behavioral Therapy for Anxiety in Youth with Autism: Paving the Way to Evidence-Based Practice

Assessment

What methods have you used in the assessment of anxiety in youth with autism?

Check all that apply:

- No experience assessing anxiety in youth with autism
- Self-report measures using anxiety scales of a larger broadband behavior rating scale, such as the anxiety scale on the Comprehensive Behavior Rating Scale (CBRS)
- Self-report measures that are a narrow band anxiety scale, such as the Multidimensional Anxiety Scale for Children (MASC)
- Records Review
- Observation
- Structured/semi-structured interview
- Unstructured or informal interview
- Clinician-administered measures such as the Anxiety Disorder Interview Schedule (ADIS)
- Clinician-administered measures specifically validated for youth with autism (e.g., ASC-ASD, ASD-CC, ADIS-IV-CP, CASI-4R, PARS, SCARED)
- Physiological assessment

Psychotherapy for Anxiety

What techniques have you used in conducting CBT for youth with anxiety and autism?

Check all that apply:

- No experience using CBT for anxiety in youth with autism
- Using only behavioral interventions (e.g., relaxation training, exposures)
- Using only cognitive interventions (e.g., cognitive restructuring)
- Using both behavioral and cognitive interventions
- Individual therapy
- Group therapy
- Psychoeducation about the nature of worry
- Identifying anxiety and worry triggers
- Identifying negative thoughts, physical sensations and/or emotions in response to worrisome situations
- Cognitive restructuring of negative/distorted beliefs
- Identifying and directly addressing intolerance of uncertainty
- Having the client monitor worry and its outcome
- Having the client monitor anxious behavior
- Having the client's family monitor anxious behavior
- Having the client's teacher(s) monitor anxious behavior

- Assigning out-of-session cognitive homework
- Assigning out-of-session behavioral experiments
- Assigning out-of-session behavioral exposure(s)
- Identifying and directly addressing positive/superstitious beliefs about worry
- Relaxation training (e.g., progressive muscle relaxation, applied relaxation training)
- Identifying and preventing safety behaviors
- Mindfulness and/or acceptance-based methods
- Focus on in-session indicators of anxiety as they arise
- Breathing retraining (e.g., diaphragmatic breathing)
- Stimulus control for worry (e.g., picking a time and place for worry)
- In-vivo worry exposure
- Imaginal worry exposure
- Narratives
- Helping clarify what is important to clients (i.e., values clarification)
- Self-help readings
- Enhancing self-efficacy in place of worry
- Creative supplements or alternatives (e.g., journal writing, song writing, drawing, painting)
- Helping the client understand the developmental roots of fears and worries
- Assertiveness training
- Imagery/visualization training
- Motivational interviewing/enhancement
- Functional communication training
- Contingency management
- Parent training
- Staff training
- ABA procedures (e.g., shaping, task analysis, natural environment teaching)
- Resolution of worrisome conflicts
- Self-control desensitization (i.e., having client hold onto worry trigger or worry outcome image while using relaxation to cope)
- Using feedback from others about the clients' anxiety
- None of the above

For the following prompts, please indicate the variable(s) you have observed in your clinical work using CBT to treat anxiety that limits successful symptom reduction for each population under question. If you have no experience using CBT for anxiety, please check, "No experience..." under each prompt.

Perceived Barriers to Treatment Progress in Youth with Autism Related to Anxiety

Anxious Symptomatology and Associated Features

Check all that apply:

- No experience treating anxiety in youth with autism
- Chronicity
- Severity

- Functional impairment (e.g., travel, work, school, social)
- Attentional or information-processing bias toward negative information
- Panic attacks
- Anxiety attacks
- Tics
- Other
- None of the above

Client beliefs about anxiety

Check all that apply:

- No experience treating anxiety in youth with autism
- Fears and worries are realistic
- Being generally anxious is part of the client's personality and unchangeable
- Problems are due to external factors (e.g., situation, other people)
- Worry helps the client prepare for the worst
- Worry actually prevents bad things from happening
- Worry helps the client to be motivated to get things done
- Worry helps the client solve problems
- Being generally anxious is abnormal/dangerous
- Anxiety is biologically based
- Loss of vigilance/anxiety will have a negative impact on relationship(s)
- None of the above

Perceived Barriers to Anxiety Treatment Progress Related to Youth with Autism

Other client problems and characteristics

Check all that apply:

- No experience treating anxiety in youth with autism
- Personality disorders
- Resistance to directiveness of treatment (e.g., noncompliance with homework)
- Chaotic lifestyle
- Inability to work independently between sessions
- Perfectionistic/obsessive style
- Premorbid functioning is limited
- Substance abuse
- Depressed mood/mood disorder
- Unwilling to give up safety behaviors
- Intellectual/cognitive/introspective ability is limited
- Limited interpersonal/social skills
- Dependency/unassertiveness
- Inability to identify automatic thoughts
- Inability to identify emotions
- Low self-esteem/self-efficacy
- Psychotic disorder
- Problems with medication (e.g., insufficient dosage, frequent changes in dosage during treatment)

- Medication refusal
- Fear of exposure and associated emotional reactions
- History of trauma
- Disruptive/defiant behavior(s)
- Client expects/requests repeated reassurance
- History of physical or sexual abuse
- Low socioeconomic status
- Physical problems
- Fear of rejection
- Diversity issues associated with ethnicity/race/ religion/sexual orientation
- Limited communication/speech/verbal fluency
- Avoidance of anxiety triggers
- Defiance/oppositional defiance
- Inconsistent attendance
- Session tardiness
- Elopement from session
- Limited attending/attention span
- In-session stimulatory behavior(s)
- Verbal aggression
- Physical aggression
- Limited/impaired executive functioning
- Cognitive inflexibility
- Behavioral rigidity
- Limited adaptive functioning
- Limited perspective-taking skills
- Clinician difficulty with differentially recognizing/diagnosing/treating anxiety symptoms
- None of the above

Client social system

Check all that apply:

- No experience treating anxiety in youth with autism
- Symptoms/dependency is reinforced/supported
- Stress is/was exceedingly high at home, school, work, and/or socially
- Trapped in a dysfunctional home, school, workplace, or social situation
- Social isolation of client
- The family's denial of diagnosis/es/impairment(s)
- The family members are very anxious
- The family members' distorted beliefs regarding client/disorder/impairment/treatment
- Lack of time due to other commitments
- The family is controlling and critical
- The family does not support treatment
- Loss of family member, partner, employment
- The family refusing participation/training
- The family's belief in non-evidence based methods/strategies/plans

- The family refusing to provide the client medication
- The family demanding too much in-session attention
- None of the above

Perceived Barriers to Treatment Progress in Youth with Autism Related to the Psychotherapy Process

Client treatment expectations

Check all that apply:

- No experience treating anxiety in youth with autism
- The therapist will do all the work to make things better
- Pessimism about therapy (e.g., due to disappointment with past therapy)
- The client will be free of all anxiety and worry
- The client will be free of all anxiety, worry, and other psychiatric comorbidities
- The client needs medication to reduce anxiety and worry
- Treatment will be brief and easy
- Symptom reduction is not enough

Family treatment expectations

Check all that apply:

- No experience treating anxiety
- The therapist will do all the work to make things better
- Pessimism about therapy (e.g., due to disappointment with past therapy)
- The client will be free of all anxiety and worry
- The client will be free of all anxiety, worry, and other psychiatric comorbidities
- The client needs medication to reduce anxiety and worry
- Treatment will be brief and easy
- Symptom reduction is not enough

Client motivation

Check all that apply:

- No experience treating anxiety in youth with autism
- Minimal motivation at the outset
- Premature termination
- Motivation decreased as the client attributes gains to medications
- Motivation decreased as some improvement occurs
- Motivation decreased as the client better understands the nature and function of worry/anxiety
- Motivation decreased due to the client's avoidance of anxiety triggers and/or directness of therapy

Therapy relationship issues

Check all that apply:

- No experience treating anxiety in youth with autism

- Therapeutic alliance with the client not strong enough from the outset
- Therapeutic alliance with family not strong enough from the outset
- The client does not feel his/her/their distress is sufficiently understood/validated
- Therapist's frustration with slow/minimal/lack of symptom reduction
- Therapist's reluctance to make the client anxious by exposing the client to anxiety-provoking stimuli (i.e., exposures)
- Therapist's negative feelings toward the client (e.g., frustration, irritation, annoyance)
- A rupture(s) in the therapeutic alliance with the client
- A rupture(s) in the therapeutic alliance with the family

Perceived Barriers to Treatment Progress Related to Treatment Setting

Private practice/outpatient center/counseling center/behavioral center

Check all that apply:

- No experience
- Time constraints
- Limited resources (e.g., treatment manuals)
- Limited peer supervision/consultation
- Limited interaction with the client's family
- Limited interaction with the client's psychiatric and/or medical providers
- Limited interaction with the client's school
- Inconsistent attendance/punctuality
- Limited ability for skill generalization
- Limited ability for in-vivo exposure(s)
- Premature termination/drop-out

School

Check all that apply:

- No experience
- Time constraints
- Limited resources (e.g., treatment manuals)
- Limited peer supervision/consultation
- Limited interaction with the student's family
- Limited interaction with the student's psychiatric and/or medical providers
- Administrative constraints (e.g., services non-permissible)
- Lack of prioritization (e.g., client misses session to finish classwork)
- Inconsistent attendance/punctuality
- Limited ability for skill generalization
- Limited ability for in-vivo exposure(s)
- Constant/premature exposure to school-based anxiety trigger(s) flooding the student
- Premature termination or drop-out

Inpatient unit

Check all that apply:

- No experience
- Time constraints
- Limited resources (e.g., treatment manuals)
- Limited peer supervision/consultation
- Limited interaction with the client's family
- Limited interaction with the client's psychiatric and/or medical providers
- Limited interaction with the client's school
- Chaotic environment
- Inconsistent attendance/punctuality
- Limited ability for skill generalization
- Limited ability for in-vivo exposure(s)
- Premature termination/drop-out

Perceived Barriers to Treatment Progress in Youth with Autism Related to Limitations of CBT

Check all that apply:

- No experience implementing CBT for anxiety in youth with autism
- Does not deal with comorbid problems/symptoms
- Insufficient focus on affect tolerance/regulation
- Simulating anxiety-provoking situations in sessions is difficult
- Relaxation does not work or causes anxiety
- Does not involve the family in treatment/limited family participation in treatment
- Does not deal with interpersonal problems
- Absence of guidelines for youth with limited cognitive functioning
- Absence of guidelines for youth with limited language/communication
- Absence of guidelines for youth with limited adaptive skills
- Worry and anxiety triggers not evident
- Absence of guidelines for dealing with resistance/noncompliance
- Does not deal with linking anxiety to other clinical issues
- Absence of guidelines for in-session behavioral modification strategies
- Not enough time for client to respond to treatment within the time frame of a CBT manual (if using a manual in regular practice)
- Strict adherence to CBT protocol
- Limited availability of structured CBT protocols
- Client not sufficiently socialized to the treatment model
- Too much time spent lecturing/on psychoeducation
- Treatment too directive
- Does not deal with the fear of interpersonal loss
- Triggers for worry and anxiety are not linked to the clients' history
- Too much between-session homework assigned
- Does not deal with comprehensive or lasting change
- Current coping skills are not linked to past

What sources do you most often use to find information on treatments for anxiety in youth with ASD?

(Check all that apply):

- School/university library
- Colleague/supervisor recommendation
- Online search engine (e.g., Google, Google Scholar)
- Academic journal
- Social media
- Clinical repertoire
- Professional list-servs
- Workshops/trainings

What are common barriers to finding and using new treatments for youth with anxiety and ASD?

(Check all that apply):

- Time restraints
- Financial restraints
- Lack of available information/treatments
- Lack of effective information/treatments
- Unsure where to find such information
- No barriers

How familiar are you with each of the following treatment curriculums on a scale from 1 (“Not At All Familiar”) to 5 (“Extremely Familiar”):

1. *Behavioral Interventions for Anxiety in Children with Autism* (Ehrenreich-May et al., 2014)

1	2	3	4	5
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2. *Interventions for Autistic Avoidance* (Moskowitz et al., 2015)

1	2	3	4	5
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3. *Facing Your Fears* (Reaven et al., 2009)

1	2	3	4	5
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3. *Multimodal Anxiety and Social Skills Interventions* (White et al., 2010)

1	2	3	4	5
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4. *Coping Cat* (Kendall et al., 2006)

1	2	3	4	5
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5. *Coping Cat-Modified* (Keehn et al., 2013)

1	2	3	4	5
---	---	---	---	---
6. *Cognitive-Behavioral Strategies for Anxiety and Escape-Autism Spectrum Disorder* (Flanagan et al., 2015)

1	2	3	4	5
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How do you determine the effectiveness of your chosen treatment program?

(Check all that apply):

- Informal observation during session(s)
- Informal observation during non-clinical time
- Progress-monitoring scales

- Semi-structured interview with client
- Semi-structured interview with client's family
- Homework review

Please rate the degree to which you rely on your clinical judgement in picking interventions for youth with anxiety and autism:

- 1 (A great deal)
- 2 (Much)
- 3 (Somewhat)
- 4 (Little)
- 5 (Never)

In thinking about your English literacy and language skills, are you able to read...

- A few words
- Simple sentences
- Basic stories
- School books
- College-level text

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