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A Review of the Role of Anxiety in Diagnosis of Children and Adolescents with Autism
Spectrum Disorder: A Paradigm Shift in Conceptualization and Diagnosis

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Clinical Research Project submitted to the Faculty of the Florida School of Professional Psychology at National Louis University in partial fulfillment of the requirements for the degree of Doctor of Psychology in Clinical Psychology.

Tampa, Florida
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The Doctorate Program in Clinical Psychology
Florida School of Professional Psychology
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CERTIFICATE OF APPROVAL

Clinical Research Project

This is to certify that the Clinical Research Project of

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has been approved by the
CRP Committee on July 31, 2023
as satisfactory for the CRP requirement
for the Doctorate of Psychology degree
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Abstract

Early evidence of co-occurring anxiety symptoms in children and adolescents with autism spectrum disorder (ASD) dates back to the first descriptions of ASD by Leo Kanner (1943) and Hans Asperger (Frith & Mira, 1992). While current research has identified anxiety disorders as one of the most prevalent co-occurring disorders in children and adolescents with ASD, little is known about the nature of the relationship between these disorders. In an effort to explain these high prevalence rates, recent research has started to investigate the relationship between these two disorders. To join these efforts, this clinical research project explored the role of anxiety in diagnosis of children and adolescents with ASD. To guide the exploration of this role, the following research questions were answered: How prevalent or significant is anxiety in children and adolescents with ASD?; How do symptoms of anxiety manifest in children and adolescents with ASD?; and How is anxiety conceptualized, assessed, and treated in ASD? Results from this literature review indicate that there are current limitations in this area of research that need to be addressed to form an accurate conceptualization of anxiety symptoms in this population. Steps to resolve these limitations are discussed and areas of further research are explored. Recommendations for accurately assessing and treating co-occurring symptoms of anxiety in youth with ASD are provided and a suggested conceptualization model based off current research is proposed.

**A REVIEW OF THE ROLE OF ANXIETY IN DIAGNOSIS OF CHILDREN AND
ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: A PARADIGM SHIFT IN
CONCEPTUALIZATION AND DIAGNOSIS**

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DEDICATION

I would like to thank everyone that has supported me throughout my academic journey. First and foremost, I would like to thank my family. To my parents, your love and dedication to your children and grandchildren is unmatched. Both of you have been the greatest examples in my life, and I am eternally grateful for all of the sacrifices that you have made so that I could be where I am today. To my siblings, thank you for all of your love and encouragement along this journey. To my wife, you are simply the best. Thank you for your endless support and for all of the sacrifices that you have made so that I could complete this journey. To my daughter, I love you so much and thank you for always being there to put a smile on my face. I love all of you so much.

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CHAPTER I: INTRODUCTION

The co-occurrence of anxiety symptoms in ASD has been noted as early as the first descriptions of ASD by Leo Kanner (1943) and Hans Asperger (Frith & Mira, 1992) in the 1930s and 1940s. Kanner and Asperger observed and described symptoms in children, including fear of common and/or novel situations and objects, high levels of generalized worries in multiple domains, fear during social interactions, and obsessions (Frith & Mira, 1992; Kanner, 1943). While the presence of anxiety has been consistently noted in ASD, the efforts to understand and explain the role and significance of this co-occurrence are more recent. Kerns, Renno, Storch et al. (2017) stated, “Co-occurrence of psychological disorders is common, and yet there is something particular about the relationship of anxiety in ASD. Anxiety is more prevalent in ASD than any other developmental and learning disorder” (p. 1).

Modern-day observations and research have focused on documenting the co-occurrence of anxiety symptoms in children and adolescents with ASD. In a prominent study in this field, White et al. (2009) conducted a comprehensive literature review where they reviewed 40 studies that examined the prevalence rates of anxiety disorders in youth with ASD. Results from this review showed that comorbidity prevalence rates of anxiety in youth with ASD ranged from 11% to 84%. While White et al. (2009) examined the “clinical” or “diagnosable” thresholds for anxiety disorders in children and adolescents with ASD, other studies have examined the “subclinical” or “subsyndrome” anxiety rates in this population. Subclinical anxiety is “anxiety symptoms that disrupt daily functioning but may not meet every diagnostic criterion, therefore never warranting a clinical diagnosis” (Muir, 2019, p. 85). In one of these studies, Caamaño et al. (2013) analyzed the subclinical psychopathology in children and adolescents with ASD and found that 76% of their participants with ASD met subthreshold or subclinical levels of anxiety.

Another study conducted by Wijnhoven et al. (2018) examined the subclinical anxiety rates in a clinical sample of 172 Dutch children (8 to 15 years old) who had previously been diagnosed with ASD. The children and their parents were administered the Spence Children's Anxiety Scale (SCAS) to measure their anxiety symptoms for this study. Results from this study indicated that 66.3% of participating children endorsed subclinical anxiety symptoms, and 81.4% of participating parents endorsed subclinical anxiety symptoms in their children. These studies on clinical and subclinical prevalence rates indicate that children and adolescents with ASD are experiencing anxiety symptoms at very high rates. While the prevalence rates may vary by specific anxiety disorder, Ghaziuddin (2002) found that anxiety is among this population's most common reasons for referral. Given the significance of these findings, the role of anxiety in diagnosing children and adolescents with ASD warrants further exploration.

Changes to the Diagnostic and Statistical Manual of Mental Disorders

On May 18, 2013, the American Psychiatric Association released the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* (American Psychiatric Association, 2013a). While many changes were made to this version, one of the most notable changes was the "Consolidation of autistic disorder, Asperger's disorder, and pervasive developmental disorder into autism spectrum disorder" (American Psychiatric Association, 2013a, p. xlii). To address the reasoning behind this consolidation, The *DSM-5* (American Psychiatric Association, 2013a) explained:

Symptoms of these disorders represent a single continuum of mild to severe impairments in the two domains of social communication and restrictive repetitive behaviors/interests rather than being distinct disorders. This change is designed to improve the sensitivity

and specificity of the criteria for the diagnosis of ASD and to identify more focused treatment targets for the specific impairments identified. (p. xlii)

The *DSM-5* (American Psychiatric Association, 2013a) classifies ASD as a developmental disorder characterized by impairments in social communication and social interactions, as well as patterns of repetitive/stereotyped behavior and/or restricted interests. These deficits in social communication and social interactions include deficits in social-emotional reciprocity, deficits in nonverbal communication used during social exchanges, and deficits in understanding relationships, specifically with forming and maintaining relationships (American Psychiatric Association, 2013a). The diagnostic criteria for the restricted and repetitive behaviors or interests included repetitive or stereotyped movements or speech, rigid and inflexible in routines and need for sameness, highly restrictive/fixated interests, and sensory hyporeactivity or hyperreactivity (American Psychiatric Association, 2013a).

In addition to the consolidation of multiple disorders into a single diagnosis of ASD, the diagnosis of social (pragmatic) communication disorder was added to the *Neurodevelopmental Disorders* section of the *DSM-5* as well. Social (pragmatic) communication disorder is primarily characterized by a deficit in the social use of verbal and nonverbal communication. These deficits include difficulty using language for social purposes, impaired ability to match communication to fit a social context, difficulty abiding by the rules of communication (e.g., taking turns in conversations), difficulty understanding ambiguous or nonliteral language, and impaired ability to utilize verbal and nonverbal cues to direct social interactions (American Psychiatric Association, 2013a). While the diagnoses of ASD and social (pragmatic) communication disorder are very similar regarding the deficits in social communication skills, the diagnosis of social (pragmatic) communication disorder does not include the restricted and

repetitive behaviors/interests/activities included in the ASD. Social (pragmatic) communication disorder can co-occur with other language disorders within the *DSM-5*; however, it cannot co-occur with ASD. The *DSM-5* also required ASD to be ruled out first before assigning the diagnosis of social (pragmatic) communication disorder (American Psychiatric Association, 2013a).

In addition to the changes that were made to the ASD diagnosis in the *Neurodevelopmental Disorders* section of the *DSM-5*, there were also multiple changes made to the *Anxiety Disorders* section. First, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD), and acute stress disorder were all removed from the *Anxiety Disorders* section (American Psychiatric Association, 2013c). The OCD diagnosis was placed in its own section labeled *Obsessive-Compulsive and Related Disorders*. The PTSD diagnosis and the acute stress disorder diagnoses were moved to the *Trauma-and-Stressor-Related Disorders* section (American Psychiatric Association, 2013a). Other notable changes within the *Anxiety Disorder* section include changes in the diagnostic criteria for social anxiety disorder, specific phobia, and agoraphobia. Previous diagnostic criteria required individuals over 18 years old to recognize their anxiety was excessive or unreasonably altered. The new *DSM-5* diagnostic criteria state, “the fear or anxiety is out of proportion to the actual danger posed by the specific object or situation and to the sociocultural context” (American Psychiatric Association, 2013a, p. 197). In addition to this alteration, the six-month symptom duration requirement was extended to all ages. This change was made to reduce the overdiagnosis of transient fears throughout the lifespan (American Psychiatric Association, 2013a). In the *DSM-5*, panic disorder and agoraphobia were no longer linked and were split into two separate diagnoses. This change was made due to the significant number of individuals with agoraphobia who did not experience panic symptoms.

These disorders were split into two diagnoses with specific criteria for each diagnosis to aid in more accurate diagnosis and treatment (American Psychiatric Association, 2013a). Another change that was made to the *Anxiety Disorder* section of the *DSM-5* was that the separation anxiety disorder diagnosis was moved from the *Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence* section and was placed into the *Anxiety Disorder* section. In addition to changing the section, the phrasing of the diagnostic criteria was altered to represent the symptomatic presentation of this disorder more accurately in the adult population (American Psychiatric Association, 2013a). Finally, the selective mutism diagnosis was also moved from the *Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence* section and was placed into the *Anxiety Disorder* section. This move was made because a significant portion of individuals with this diagnosis also experience impaired levels of anxiety (American Psychiatric Association, 2013a).

On March 18th, 2022, the American Psychiatric Association released the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)* (American Psychiatric Association, 2022a). This was the first revision made to the *DSM-5* since it was released in May 2013. In the *DSM-5-TR*, there were notable revisions to the ASD diagnostic criteria as well as the social anxiety disorder diagnostic criteria. The revision for the ASD was within the *Criterion A* section (American Psychiatric Association, 2022a). The *DSM-5-TR Autism Spectrum Disorder Fact Sheet* stated, “Criterion A phrase ‘as manifested by the following’ was revised to read ‘as manifested by all of the following’ to improve the intent and clarity of the wording” (American Psychiatric Association, 2022b, p. 1). Regarding social anxiety disorder, the term “social phobia” in parentheses in the *DSM-5* was removed in the *DSM-5-TR*. This term was included in parentheses in the *DSM-5* to aid in the transition in

nomenclature from social phobia to social anxiety. However, it was determined that the field had successfully adopted the new name of social anxiety disorder, so the old term, “social phobia”, was removed from the *DSM-5-TR* (American Psychiatric Association, 2022b). While the *DSM-5-TR* was released prior to the publication of this clinical research project, the recent release date limits access to new research studies based on *DSM-5-TR* diagnostic criteria. Due to this, the majority of the research used throughout this clinical research project primarily utilized studies based on *DSM-5* diagnostic criteria and addresses issues that are more related to the *DSM-5*.

The changes made have implications with every new revision to the *Diagnostic and Statistical Manual of Mental Disorders*. While the changes to the *DSM-5-TR* appear to be relatively minor for anxiety disorders and ASD, even minor changes can impact the future of research and clinical implementation of treatment. The changes that were made in the *DSM-5* regarding ASD diagnosis were extensive and had significant implications that spanned several domains. According to the *DSM-5 Autism Spectrum Disorder Fact Sheet* (2013b) that the American Psychiatric Association created, “The revised diagnosis represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders” (p. 1). The *DSM-5 Autism Spectrum Disorder Fact Sheet* (2013b) also states that Susan Swedo, MD, and her Neurodevelopmental Work Group at the National Institute of Mental Health were responsible for much of the research and recommendations that contributed to the *DSM-5* diagnosis of ASD. In the *DSM-5 Autism Spectrum Disorder Fact Sheet* (2013b), Susan Swedo, MD, and the Neurodevelopmental Work Group commented that *DSM-5* criteria for ASD were “a better reflection of the state of knowledge about autism” and they believe that “a single umbrella disorder will improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially changing the number of children being diagnosed” (p. 1). While it

appears that the goal of the American Psychiatric Association was to create a more accurate and scientifically based approach to diagnosing this population, there have been many critics of that change in the diagnostic criteria.

Concerns About the Changes Made to the DSM-5

Upon the release of the *DSM-5*, there were many concerns about how the shift to the ASD diagnostic criteria would impact the field. While many professionals offered their criticisms and related evidence about this subject, most of the concerns outlined in the literature have similar themes and can be organized into certain domains. One of the most frequently noted concerns in the literature is that mental health professionals would need to be trained on the *DSM-5* criteria for ASD to properly diagnose new patients, as well as confirm the diagnoses of individuals who have been previously diagnosed with one of the disorders that were encapsulated by the autism spectrum. The concern was that this process would require significant time to properly train all the clinicians on the *DSM-5* criteria, which could lead to delays for individuals seeking a diagnosis and accessing the related services (Ritvo, 2012).

The second domain is in the realm of continuity of service delivery for individuals previously diagnosed using the criteria set forth in the *DSM-IV*. When the *DSM-5* was first released in 2013, many treatment facilities and service providers were required to re-diagnose their patients using the new diagnostic criteria set forth by the *DSM-5*. Most treatment facilities have administrative requirements that their patients have updated diagnoses to continue receiving services (Ritvo, 2012). At the time of the conversion to the *DSM-5* diagnostic criteria, there was widespread apprehension that many individuals previously diagnosed using the *DSM-IV* criteria would no longer meet the diagnostic criteria delineated in the *DSM-5*. Volkmar and Reichow (2013) stated, “Despite the name change to autism spectrum disorder, the concept actually

proposed is apparently more restricted than the DSM-IV approach” (p. 3). Several studies have been conducted and yielded evidence that the *DSM-5* diagnostic criteria are less sensitive than the *DSM-IV* diagnostic criteria (Gibbs et al., 2012; Matson, Hattier, et al., 2012; Matson, Kozlowski et al., 2012; Mayes, Black et al., 2013; McPartland et al., 2012; Taheri & Perry, 2012; You et al., 2011). While the outcomes of these studies vary depending on the variables analyzed, the results suggest that approximately 20% to 40% of the individuals diagnosed by the *DSM-IV* criteria do not meet the diagnostic criteria set forth in the *DSM-5* for ASD (Ritvo, 2012).

Regarding the populations found to be at the most risk of losing their diagnoses, Mattila et al. (2011) found that the *DSM-5* criteria were less sensitive to individuals previously diagnosed with Asperger’s syndrome and high-functioning ($IQ \geq 70$) individuals previously diagnosed with autistic disorder. Additionally, Gibbs et al. (2012) found that children previously diagnosed with pervasive developmental disorder—not otherwise specified (PDD-NOS) were also at a particularly elevated risk of not meeting the *DSM-5* diagnostic criteria. Findings from their study also indicated “DSM-5 is likely to reduce the number of children who will be diagnosed with an ASD in the future due to the more stringent requirements in terms of the number of criteria that must be met” (Gibbs et al., 2012, p. 1755).

While many studies show that the *DSM-5* diagnostic criteria are less sensitive than the *DSM-IV* diagnostic criteria, there have also been studies that refute those claims. One such study, conducted by Huerta et al. (2012), found that the *DSM-5* criteria identified 91% of individuals previously diagnosed with the *DSM-IV* PDD-NOS. Another study by Mazefsky et al. (2012) found that the *DSM-5* diagnostic criteria identified 93% of high-functioning participants previously diagnosed with autistic disorder using the *DSM-IV* diagnostic criteria. While the major difference in the findings suggests the need for additional research, the fact remains that

losing their diagnosis and the related services during the switch from the *DSM-IV* criteria to the *DSM-5* diagnostic criteria would be detrimental to any individual. Even in the studies that boasted high rates of correlation, a substantial percentage of individuals may be in jeopardy of losing their diagnosis and the services often only available with the proper diagnosis.

The domain arguably the most impacted by the transition to the *DSM-5* diagnostic criteria for ASD is the research domain. Upon the release of the *DSM-5*, one of the major concerns was how studies that were conducted utilizing *DSM-IV* ASD diagnostic criteria would generalize or translate to studies that utilized *DSM-5* ASD diagnostic criteria. It was also feared that this transition to the *DSM-5* ASD diagnostic criteria would significantly impact the long-term studies still in progress, such as epidemiological and longitudinal studies originally based on the *DSM-IV* criteria (Volkmar & Reichow, 2013). Regarding this concern, Ritvo (2012) mentioned that many of these epidemiological and longitudinal studies utilized screening instruments based on *DSM-IV* diagnostic criteria for ASD and warned that the data from these experiments “will not be straightforwardly compatible with the data or results produced using the new *DSM-5* criteria” (p. 2021). This would create *DSM-IV* and *DSM-5* data sets that would be unable to be pooled together and would impact research dating back to 1994 when the *DSM-IV* was released (Ritvo, 2012). Another concern that arose when the changes to the *DSM-5* were announced was the length of time it would take for researchers to develop new protocols for diagnostic assessments and screening instruments based on the *DSM-5* diagnostic criteria and meet adequate validity and reliability requirements. Considerable time may be required for these measures to be developed and distributed and for providers to be trained on how to administer, score, and interpret the measures properly. These delays could cause further interruption to research and potentially impact individuals attempting to receive an accurate diagnosis and gain access to the appropriate

services. The concerns about research, like the majority of the other issues that have been outlined, are a topic of much debate. While it is likely that there will continue to be some lingering hesitation regarding the generalizability of ASD research when using *DSM-IV* variables versus using *DSM-5* variables, there have been studies indicating generalizability and continuity between these two data sets. Mazefsky et al. (2012) stated, “These results demonstrate that, for the most part, the symptoms proposed for ASD in DSM-5 are evident among prior verbal research participants, indicating likely continuity between DSM-IV and DSM-5 research samples” (p. 1240). This illustrates that while there may be some hesitancy, there is evidence that supports the generalizability of *DSM-IV* research and *DSM-5* research regarding ASD.

Another concern, outlined by Volkmar and Reichow (2013), focused on how the changes in The World Health Organization’s *International Statistical Classification of Diseases and Related Health Problems, Eleventh Edition (ICD-11)* (World Health Organization, 2022a) would align with the *DSM-5* criteria for ASD. Historically, the timing of the releases of these classification systems has not aligned, making it difficult for collaboration. The release of the *DSM-5* and the *ICD-11* was no exception to this pattern. The *DSM-5* was released in May 2013, but the *ICD-11* was not introduced until May 2019 and did not go into effect until January 2022 (American Psychiatric Association, 2013a; World Health Organization, 2022b). For the latest classification systems, the creators of both systems made it a priority to collaborate before releasing the latest editions of their classification systems (American Psychiatric Association, 2022a). The American Psychiatric Association task force for the *DSM-5-TR* created specialized groups that were tasked with collaborating with the World Health Organization *ICD-11* task force with the goal of harmonizing the two classification systems as much as possible (American Psychiatric Association, 2022a). According to the *DSM-5-TR* (American Psychiatric

Association, 2022a), the harmonization between the *DSM-5-TR* and the *ICD-11* was important for three reasons. First, the *DSM-5-TR* (American Psychiatric Association, 2022a) states that “two major classifications of mental disorders hinder the collection and use of national health statistics, the design of clinical trials aimed at developing new treatments, and the consideration of global applicability of the results by international regulatory agencies” (p. 13). The second reason outlined by the *DSM-5-TR* (American Psychiatric Association, 2022a) was that “the existence of two classifications complicates attempts to replicate scientific results across national boundaries” (p. 13). The last reason outlined by the *DSM-5-TR* (American Psychiatric Association, 2022a) was “even when the intention was to identify identical patient populations, DSM-IV and ICD-10 diagnoses did not always agree” (p. 13). While these two classification systems have not always aligned, the American Psychiatric Association believes their collaborative efforts with the World Health Organization to release the *DSM-5-TR* and the *ICD-11* were successful (American Psychiatric Association, 2022a). The *ICD-11* classifies ASD as:

Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational, or other important areas of functioning and are usually a pervasive feature of the individual’s functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the

spectrum exhibit a full range of intellectual functioning and language abilities. (World Health Organization, 2022a, Autism Spectrum Disorder section, para. 1)

Prior to the release of the *ICD-11* in 2019, it was unknown whether the World Health Organization would align the *ICD-11* criteria with the *DSM-5* criteria, particularly regarding significant changes made to the ASD diagnosis. It is now known that the *DSM-5-TR* and the *ICD-11* were able to align closely, and the American Psychiatric Association stated that they believe the *DSM-5-TR* and the *ICD-11* are as closely aligned as they have been since the *DSM-II* and *ICD-8* (American Psychiatric Association, 2022a). If the two classification systems would have failed to align, there would have been major disparities between the research conducted in the United States and the rest of the world.

Examining the Role of Anxiety in Children and Adolescents with ASD

When examining the role of anxiety in ASD in children and adolescents, it is important to examine them separately first. In 2020, the Center for Disease Control (CDC) released an article discussing their Autism and Developmental Disabilities Monitoring (ADDM) network (Maenner et al., 2020). In this article, the CDC explained that the ADDM is “an active surveillance program that provides estimates of the prevalence of ASD among children aged 8 years whose parents or guardians live in 11 ADDM Network sites in the United States” (Maenner et al., 2020, p. 1). The ADDM began collecting prevalence data across the United States in 2016, and in 2020, they reported that the prevalence rate for ASD was 1 in 54 children (Maenner et al., 2020). The ADDM also reported that ASD was 4.3 times more prevalent in males than females (Maenner et al., 2020).

Regarding anxiety disorders, most of the prevalence rate data for the United States is derived from the National Survey of Children’s Health (NSCH). According to the U.S. Census

Bureau (2022), the NSCH is an annual questionnaire managed by the Maternal and Child Health Bureau of the Health Resources and Services Administration and distributed through the U.S. Census Bureau. The NSCH is designed to assess multiple areas related to the physical and emotional health of children ages 0–17 and provide data at the national and state levels (U.S. Census Bureau, 2022). In 2016, the NSCH was redesigned and moved from a telephone survey to a mail and Internet-based survey due to declining response rates and fewer household landlines (Centers for Disease Control and Prevention, 2021). Since 2016, the data from the NSCH have been used widely in research to report nationally representative prevalence estimates of anxiety problems in children and adolescents. When analyzing the 2016 NSCH data, Ghandour et al. (2019) reported that the prevalence rate of anxiety disorders in children ages 3–17 was 7.1% and noted that the prevalence rate significantly increased by age. A study by Lebrun-Harris et al. (2022) examined the NSCH data from 2016 to 2020 to determine if they were able to identify any trends that developed within that time frame. From 2016 to 2020, 174,551 children were assessed using the NSCH and were included in this study (Lebrun-Harris et al., 2022). This study showed that the prevalence rates of anxiety in children and adolescents increased yearly since 2016. The prevalence rate in 2016 was 7.1%, and by 2020, the prevalence rate had increased to 9.2%, equivalent to a 29% increase. (Lebrun-Harris et al., 2022).

The most recent studies examined the impact COVID-19 has had on children and adolescents, particularly concerning their mental health. In a meta-analysis, Racine et al. (2021) examined 29 research studies related to the impact of COVID-19 on the anxiety and depressive symptoms of children and adolescents. Using a random-effect meta-analysis model, Racine et al. (2021) found that pooled prevalence estimates of clinically elevated anxiety symptoms were 20.5%. They also found that the prevalence rates of anxiety in children and adolescents were

more elevated in studies collected later in the pandemic (Racine et al., 2021). While the prevalence rates of anxiety in children and adolescents were already increasing in the years leading up to the COVID-19 pandemic, these findings suggest that COVID-19 contributed to a drastic spike in the prevalence rates that may not have been as severe if not for the effects of the pandemic. The impact of COVID-19 is discussed in further detail in a subsequent chapter of this clinical research project.

When examining the role of anxiety in ASD in children and adolescents, research findings suggest a significant correlation between the two diagnoses (Ghaziuddin, 2002; Kerns, Renno, Storch, et al., 2017; Mukaddes & Fateh, 2010; Muris et al., 1998; Salazar et al., 2015; van Steensel et al., 2011). The consistency with which studies find high levels of correlation between these two disorders warrants further investigation into how anxiety is conceptualized concerning ASD. Kerns, Renno, Storch, et al. (2017) noted “Clinically, practitioners working with people with ASD and anxiety have often noted that aspects of their clients’ anxiety presentations appear to be distinct to ASD and often different to presenting symptoms typically seen in anxious individuals without ASD” (p. 33). This feeling is all too familiar to practitioners with extensive experience working with this population. This suggests the possibility of inherent anxiety criteria that should be considered part of the ASD diagnosis instead of anxiety being a co-occurring or comorbid diagnosis in individuals with ASD.

Statement of Problem

Current research supports the notion of a correlation between anxiety symptoms and ASD. However, there has been significant variability in the prevalence rates across studies (van Steensel et al., 2011; White et al., 2009). The variability across these studies is likely due to various conceptual and methodological factors. Examples of these factors include demographic

variables, sample composition, assessments utilized, language/communication abilities, emotional literacy, intellectual functioning levels, the severity of autism symptoms, other comorbid disorders, types of anxiety symptoms that are experienced, and how they are operationalized across studies (Kerns & Kendall, 2012; Kerns, Renno, Storch, et al., 2017). In subsequent chapters, these conceptual and methodological factors are explored in greater detail. These factors that influence the variability across prevalence rates in research studies create a problem that is cascading. To clarify, these inconsistent results create uncertainty about how truly prevalent anxiety is in individuals with ASD. This uncertainty makes it difficult to understand the nature of the relationship between anxiety and ASD and how it manifests in this population. Consequently, without a firm understanding of the role that anxiety plays in ASD and how it manifests in this population, it is difficult to define properly in research. Without research evidence and support, it is challenging for practitioners to assign proper diagnoses in clinical settings. Additionally, without the supporting research, it is challenging to understand the etiology of anxiety in ASD and provide a conceptualization of the nature of the relationship between these disorders. This makes it difficult for practitioners to provide evidence-based interventions and other treatments.

While there is variability within the studies that examine prevalence rates of anxiety in ASD, there have been multiple systematic reviews and meta-analyses conducted on this topic and the results from these reviews indicate that anxiety is highly prevalent in children and adolescents with ASD (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). With enough research evidence to support the prevalence of anxiety in ASD, the current issue within the research seems to be understanding the role of anxiety in ASD. Current research has struggled to clearly define the role of anxiety in ASD, which has limited the

advancements in this area, particularly with identification, classification, and treatment within this population. This clinical research project focused on better defining the role of anxiety in ASD.

Purpose of the Study

Similar to the cascading nature of the problem stated above, it is hypothesized that the impact of this clinical research project could also have a cascading effect. The main purpose of this clinical research project was to review the available literature to define better the role of anxiety in children and adolescents with ASD to provide a more accurate conceptualization of anxiety in this population that could have a widespread influence in this area of study. To accomplish this, the existing literature was critically analyzed in an effort to better define, categorize, and operationalize the nature of the relationship between anxiety and ASD. This analysis included further exploration into the current understanding of the relationship between anxiety and ASD as well as the exploration of alternative views that could potentially shift the way that anxiety is conceptualized in relation to ASD.

Currently, anxiety disorders and ASD are viewed as separate, co-occurring/comorbid disorders. Psychiatric comorbidity rates are high in this population, with 70% of individuals with ASD having at least one psychiatric comorbidity and 41% of individuals having two or more comorbid disorders (Simonoff et al., 2008). Within the *Autism Spectrum Disorder* section of the *DSM-5*, anxiety disorders are listed in the *Comorbidity* section but are not mentioned in the *Differential Diagnosis* section (American Psychiatric Association, 2013a). In the *DSM-5-TR*, anxiety disorders are listed in the *Comorbidity* section as well as the *Differential Diagnosis* section (American Psychiatric Association, 2022a). OCD is also listed in the *Differential Diagnosis* section of the *DSM-5-TR*, and while OCD was removed from the *Anxiety Disorders*

section of the *DSM-5*, it is still covered in this clinical research project due to its close overlap with ASD and anxiety disorders. In the *Differential Diagnosis* section, the *DSM-5-TR* references the overlap of the core symptoms of ASD and the symptoms of anxiety disorders and the challenges that this overlap poses for accurate classification and diagnosis. A similar explanation is provided for OCD in the *Differential Diagnosis* section (American Psychiatric Association, 2022a). Including these statements in the *DSM-5-TR* suggests that the American Psychiatric Association recognizes that differentiating these symptoms is difficult for researchers and practitioners. These issues with symptom differentiation can potentially jeopardize future research and could have clinical implications in the areas of assessment, diagnosis, and treatment. Difficulty with symptom identification and differentiation is particularly dangerous in clinical settings where individuals are receiving diagnoses and treatment. If practitioners are unable to accurately differentiate the symptoms of anxiety from the core ASD symptoms, then there is a risk that the anxiety symptoms may go unnoticed. If these anxiety symptoms are unnoticed, they may either go untreated or the treatment delivered may be detrimental to the individual because their symptoms of anxiety have not been accounted for.

A meta-analysis conducted by Scott et al. (2022) examined the course of untreated anxiety disorders and found that the impact of untreated anxiety disorders is an area of research that is poorly understood due to limited research. Scott et al. (2022) went on to explain that obtaining data sets in this area is difficult because, often, people receive treatment for their symptoms of anxiety, making them ineligible to use as part of the data sets. Ethical requirements also impact the ability to obtain adequate data sets. Given that there are effective treatments for anxiety that are known and available, researchers would violate these ethical requirements if they instructed participants to simply do nothing about the symptoms of their anxiety (Scott et al.,

2022). While the research in this area is limited, some studies have examined the effects of untreated anxiety (Adler Nevo et al., 2014; Hill et al., 2016; Kendall et al., 2004; Scott et al., 2022). Findings from these studies suggest that without treatment, anxiety disorders are unlikely to remit and are likely to have a chronic course into adulthood (Hill et al., 2016; Scott et al., 2022). In a long-term follow-up study, Kendall et al. (2004) found that untreated anxiety disorders in adolescents increased the risk of developing chronic anxiety as well as other issues such as depression, suicidal ideation, suicide attempts, and substance abuse disorders. It is important to note that the samples used in these studies were comprised of a neurotypical population. Research on untreated anxiety in individuals with ASD is an even more limited area of study. This is an area of research that warrants further investigation because children and adolescents with ASD have been found to have higher levels of anxiety and more severe symptoms of anxiety when compared to clinically referred children and adolescents (MacNeil et al., 2009; van Steensel & Heeman, 2017). In addition to ascertaining an adequate sample and abiding by ethical requirements, another reason for the limited research in this area may be because the relationship between anxiety and ASD is not fully understood.

With the ongoing methodological and conceptual challenges associated with research in this area and the continued difficulties with assessment and treatment in the clinical setting, it is important to question the current understanding of the role of anxiety in ASD. Is the current view of anxiety and ASD being separate and co-occurring/comorbid disorders limiting the advancements that can be made in this area? Can changing the way anxiety in ASD is conceptualized unlock future research and assist clinicians with clarifying diagnosis and furthering their understanding of anxiety's role in ASD? This clinical research project explored other potential ways that the role of anxiety can be conceptualized in ASD. One of the ways

explored is whether anxiety can be classified as a core diagnostic criterion within the ASD diagnosis.

Literature Review Research Questions

To explore this topic, a series of literature review research questions guided this clinical research project. These questions included:

1. How prevalent or significant is anxiety in children and adolescents with ASD?
2. How do symptoms of anxiety manifest in children and adolescents with ASD?
3. How is anxiety conceptualized, assessed, and treated in ASD?

Research Procedure

To complete this clinical research project, databases such as ProQuest and EBSCO were utilized to identify and analyze peer-reviewed articles, dissertations, and other professional sources related to the role of anxiety in ASD. Search terms included prevalence rates of ASD, prevalence rates of anxiety disorders, comorbidity of ASD and anxiety disorders, the role of anxiety in ASD, changes to *DSM-5*, changes to *DSM-5-TR*, the impact of COVID-19 pandemic on children and adolescents with ASD, the impact of COVID-19 pandemic on children and adolescents' anxiety, and overlap of ASD symptoms and anxiety disorder symptoms. The reference sections of each peer-reviewed article were also utilized to identify additional reference articles.

CHAPTER II: HOW PREVALENT OR SIGNIFICANT IS ANXIETY IN CHILDREN AND ADOLESCENTS WITH ASD?

Evidence of the co-occurrence of anxiety symptoms in ASD dates back to the observations of Leo Kanner and Hans Asperger, who were credited with providing the first descriptions of ASD (Frith & Mira, 1992; Kanner, 1943). These observations included experiencing a high level of generalized worries in multiple domains, obsessions, fear during social interactions, and fear of common and/or novel situations (Frith & Mira, 1992; Kanner, 1943). While the diagnostic criteria for ASD and anxiety disorders have changed since the observations made by Kanner and Hans, the co-occurrence of anxiety symptoms in ASD continues to be a topic of research that garners significant attention.

Current research studies have found high co-occurrence rates between ASD and other psychiatric disorders (Ivanović, 2021; Kirsch et al., 2020; Lecavalier et al., 2019; Mutluer et al., 2022; Salazar et al., 2015; Simonoff et al., 2008). These studies show that anxiety disorders are among the most frequently diagnosed comorbid disorders in children and adolescents with ASD (Ivanović, 2021; Kirsch et al., 2020; Lecavalier et al., 2019; Mutluer et al., 2022; Salazar et al., 2015; Simonoff et al., 2008) and anxiety is one of the most common reasons for referral in this population (Ghaziuddin, 2002). As stated previously, the comorbid prevalence rates of anxiety disorders in children and adolescents with ASD range from 11% to 84% (Muris et al., 1998; White et al., 2009). When research studies produce a wide range of prevalence rates, it is often helpful to utilize relevant meta-analysis studies to gain a better understanding of where the average ranges fall across studies. Within this area of research, two cornerstone meta-analysis studies are frequently referred to by other studies. The first study was conducted by van Steensel et al. (2011), and the second was conducted by van Steensel and Heeman (2017). In the first

study, van Steensel et al. (2011) systematically reviewed the literature and identified 31 studies that fit their inclusion criteria, encapsulating 2,121 child and adolescent participants with ASD. All of the studies used in this meta-analysis utilized standardized questionnaires and/or diagnostic interviews to assess for anxiety disorders. It is important to note that this study was published in 2011, so the results are based on the *DSM-IV* diagnostic criteria for anxiety disorders and ASD. Nevertheless, while this study's results are based on *DSM-IV* diagnostic criteria, the findings are still relevant to this clinical research project. Overall, the meta-analysis conducted by van Steensel et al. (2011) found that 39.6% of children and adolescents with ASD also meet diagnostic criteria for at least one anxiety disorder. Regarding the prevalence rates of specific anxiety disorders, specific phobia was the most prevalent, with 29.8% of the sample meeting the diagnostic criteria for this disorder (van Steensel et al., 2011). OCD had the next highest prevalence rate at 17.4%, followed by social anxiety disorder at 16.6%, agoraphobia at 16.6%, generalized anxiety disorder at 15.4%, separation anxiety disorder at 9.0%, and panic disorder at 1.8% (van Steensel et al., 2011). In addition to providing prevalence rates of anxiety disorder in children and adolescents with ASD, this meta-analysis also intended to identify the "moderator effects," factors that potentially impact the variability in the prevalence rates across studies (van Steensel et al., 2011, p. 309). The moderators examined in this meta-analysis included age, IQ, assessment method, informant, and ASD subtype. Results indicated that age, IQ, and ASD subtype all had a moderating effect on the prevalence rates within the studies included in the meta-analysis (van Steensel et al., 2011). These moderating effects are explored further in subsequent chapters.

The second cornerstone meta-analysis was conducted by van Steensel and Heeman (2017). The purpose of this study was to "meta-analytically estimate the difference in anxiety

levels between children with ASD and typically developing children, and between children with ASD and clinically referred children” (van Steensel & Heeman, 2017, p. 1754). Additionally, van Steensel and Heeman (2017) examined age and IQ to determine if these factors had any moderating effects on the results. For this study, van Steensel and Heeman (2017) selected 83 studies that met their inclusion criteria to include in their meta-analysis. Similarly to the meta-analysis conducted in 2011, this study also had specific inclusionary criteria that required each study to have each of the following: the articles had to be published in English; an ASD group and a comparison group; standardized questionnaires to measure anxiety symptoms; and the average age of the participants had to be less than 19 years old (van Steensel & Heeman, 2017). Studies were excluded for the following reasons: if the study did not report on empirical data; if the study only reported data about case studies; if the study only used other-informant reports and did not contain self or parent/guardian reports; or if researchers utilized interviews rather than questionnaires (van Steensel & Heeman, 2017). This meta-analysis by van Steensel and Heeman (2017) yielded a number of significant findings that provided a strong foundation for future research in this area. First, they found that when compared to a typical developing sample, children and adolescents with ASD had much higher levels of anxiety (van Steensel & Heeman, 2017). They also found that when compared to the clinically referred sample, children and adolescents with ASD had more elevated levels of anxiety (van Steensel & Heeman, 2017). Third, van Steensel and Heeman (2017) found that the type of comparison group impacted the findings. When the ASD group was compared to a group that struggled with externalizing problems or developmental problems, the ASD group had higher levels of anxiety. However, when the ASD group was compared to a group with internalizing problems, the results were inconsistent (van Steensel & Heeman, 2017). The fourth finding was regarding the relationship

between IQ and anxiety symptoms in the ASD group and the typical developing group. They found that the disparity of anxiety symptoms between the ASD group and the typically developing group increases as IQ increases (van Steensel & Heeman, 2017). Finally, van Steensel and Heeman (2017) also found that age has a moderating effect between the ASD group and the clinically referred group. The difference in anxiety between the ASD group and the clinically referred group increases as age increases (van Steensel & Heeman, 2017). These results suggest that high-functioning adolescents with ASD may be at an increased risk for developing anxiety disorders; therefore, this population should be carefully monitored for anxiety problems (van Steensel & Heeman, 2017). While this meta-analysis did not provide prevalence rates, it did highlight the prominence of anxiety disorders in children and adolescents with ASD, and it provided further information about the levels of anxiety experienced in this population in comparison to other groups.

Another meta-analysis that is smaller but is often referred to was conducted by Kerns, Renno, Storch, et al. (2017). For this meta-analysis, Kerns, Renno, Storch, et al. (2017) utilized 17 studies that examined the prevalence rates of anxiety disorders in children and adolescents with ASD. Of the 17 studies selected, 12 focused on children and adolescents, four focused on adults, and 1 examined social anxiety in adolescents and adults (Kerns, Renno, Storch, et al., 2017). To be included in this meta-analysis, the study had to utilize a diagnostic interview corresponding with specific *DSM* or *ICD* criteria. From the meta-analysis, Kerns, Renno, Storch, et al. (2017) found that specific phobia was the most common anxiety disorder in individuals with ASD, with a 30% prevalence rate. Data from the meta-analysis also indicated that while specific phobia was the most prevalent disorder, it was most common in children, and there was a significant reduction in prevalence rates in adolescents and adults (Kerns, Renno, Storch, et al.,

2017). OCD was found to have the second highest prevalence rate at 17%, followed by social anxiety disorder at 17%, agoraphobia at 17%, generalized anxiety disorder at 15%, separation anxiety at 9%, and panic disorder at 2% (Kerns, Renno, Storch, et al., 2017). The findings in this meta-analysis are very similar to the results from the meta-analysis conducted by van Steensel et al. (2011).

The last meta-analysis available in this area was by Hollocks et al. (2018). While this study examined anxiety and depression in adults with ASD, the results were reported in current and lifetime prevalence rates. The lifetime rates were beneficial to review for this clinical research project due to the size of the study and the benefits of meta-analysis data. The sample for this meta-analysis included 35 studies; 27 studies examined anxiety, 29 studies examined depression, and 21 studies measured both. The studies that examined anxiety had 26,070 participants, and 7 of the 35 included adolescents in the sample (Hollocks et al., 2018). Overall, this meta-analysis found that the prevalence of any current anxiety disorder was 27% for their sample, and the lifetime prevalence rate was 42% (Hollocks et al., 2018).

Regarding specific anxiety disorders, Hollocks et al. (2018) found that social anxiety had a current prevalence rate of 29% and a lifetime prevalence rate of 20%. OCD had a prevalence rate of 24% and a lifetime prevalence rate of 22%. The current prevalence rate for generalized anxiety disorder was 18%, and the lifetime prevalence rate was 26%. The prevalence rate for panic disorder was 15%, and the lifetime prevalence rate was 18%. Specific phobia's current and lifetime prevalence rates were 6% and 31%, respectively. For separation anxiety disorder, the current prevalence rate was 3%, and the lifetime prevalence rate was 21%, respectively (Hollocks et al., 2018). When discussing their investigation, Hollocks et al. (2018) noted that their results were similar to other meta-analysis studies conducted with children and adolescents

18 years old and younger. While these results are similar to the other meta-analyses conducted in this area of research, Hollocks et al. (2018) indicated that one of their major limitations in this meta-analysis was the high heterogeneity between studies. Furthermore, they suggested that finding ways to reduce the degree of heterogeneity between studies would provide more accurate results, which could help draw more accurate conclusions about anxiety in this population (Hollocks et al., 2018). The concept of heterogeneity between studies is discussed further in subsequent chapters.

It is important to note that these meta-analyses provide information about prevalence rates based on the percentage of the samples that meet or exceed the clinical threshold for an anxiety disorder diagnosis. The results from these studies provide prevalence rates in terms of whether they meet diagnostic thresholds for a diagnosis. These studies do not account for the percentage of the samples that do not meet the diagnostic threshold but are still experiencing subclinical anxiety symptoms that are still disruptive to the individual's overall functioning. Research on subclinical anxiety in children and adolescents with ASD is very limited. However, the available studies indicate that between 66.3% and 76% of the samples experienced disruptive subclinical anxiety but did not meet the threshold for a diagnosis (Caamaño et al., 2013; Wijnhoven et al., 2018). Results from Wijnhoven et al. (2018) also indicated that 81.4% of participating parents in their study endorsed subclinical anxiety symptoms in their children. Researchers have suggested that children and adolescents with ASD may experience various anxiety symptoms unique to ASD (Kerns, Renno, Storch, et al., 2017). This constellation of anxiety symptoms manifests in a unique way that is commonly referred to in the research as an "atypical presentation" (Kerns et al., 2014). It is referred to as an atypical presentation because the constellation of symptoms experienced still causes significant distress but does not align with

DSM criteria and therefore does not always result in a formal diagnosis (Kerns et al., 2014). It is theorized that this atypical presentation could account for the high subclinical anxiety rates because the presentation of anxiety in this population does not always align with *DSM* diagnostic criteria for anxiety disorders and thus produces high subclinical rates (Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017). Traditional versus atypical anxiety presentations in children and adolescents with ASD are discussed further in subsequent chapters.

Prevalence Rates of Each Anxiety Disorder in Children and Adolescents with ASD

The following section examines further the prevalence of each anxiety disorder in children and adolescents with ASD and its impact on this population.

Specific Phobia

In meta-analysis studies, specific phobia has been found to be the most common anxiety disorder for children and adolescents with ASD (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). The American Psychiatric Association describes specific phobia as:

A specific phobia is excessive and persistent fear of a specific object, situation or activity that is generally not harmful. Patients know their fear is excessive, but they can't overcome it. These fears cause such distress that some people go to extreme lengths to avoid what they fear. (American Psychiatric Association, 2021, Specific Phobia section, para.1)

The *DSM-5* (American Psychiatric Association, 2013a) states that the 6-to-12-month prevalence rate for this disorder in children in the general population is approximately 5%, and the prevalence rate in the general population for adolescents is approximately 16%. The *DSM-5* also reports that animal, natural environment, and situational phobias are more commonly

experienced by females at an approximate rate of 2:1, while blood, injection, and injury are typically experienced equally by males and females (American Psychiatric Association, 2013a). Concerning development and course in the general population, the *DSM-5* (American Psychiatric Association, 2013a) states, “specific phobia usually develops in early childhood, with the majority of cases developing prior to age 10 years. The median age at onset is between 7 and 11 years, with the mean at about 10 years” (p. 200).

When examining the prevalence rates of specific phobias in children and adolescents with ASD, these rates appear to be significantly higher than those in the general population without ASD. As stated previously, meta-analysis studies that examine the prevalence rates of anxiety disorders in children and adolescents with ASD consistently report specific phobia as one of the most prevalent anxiety disorders experienced within this population (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). In their meta-analysis studies, Kerns et al. (2014) and van Steensel et al. (2011) found that the prevalence rate of specific phobia was 30% in children and adolescents with ASD, and Hollocks et al. (2018) found in their meta-analysis that the lifetime prevalence rate of specific phobia was 31%. These meta-analysis studies provide prevalence rates that are the collective average of many studies. While the prevalence rates in these meta-analysis studies were between 30–31%, the prevalence rates of the individual studies that were included in the meta-analyses varied significantly. The study by van Steensel et al. (2011) included 16 studies that examined specific phobia in children and adolescents with ASD. From these 16 studies that comprised their meta-analysis, the prevalence rates ranged from 8.5% (Simonoff et al., 2008) to 67.2% (Witwer & Lecavalier, 2010). Kerns, Renno, Storch, et al. (2017) examined eight studies that examined specific phobia in children and adolescents and found the same ranges in prevalence rates. Kerns, Renno, Storch, et al. (2017)

did note that they believe that low prevalence rates in the Simonoff et al. (2008) study skewed the results because of the additional requirements they placed on evidence of functional impairment to receive a diagnosis of specific phobia. Kerns, Renno, Storch, et al. (2017) indicated that they believed the 31–67% range was a more accurate representation of the prevalence rate of specific phobia in this population.

Concerning the development and course of specific phobia in children and adolescents with ASD, research is very limited in this area. Studies about specific phobias in children and adolescents with ASD, such as Mukaddes and Fateh (2010) and Salazar et al. (2015), found trends that were similar to those noted in the *DSM-5* about the development and course of specific phobia in the general population. Both of these studies found that the prevalence rates of specific phobias decreased as the age of their participants increased. Mukaddes and Fateh (2010) found that 21% of their child participants met the diagnostic criteria for a specific phobia. However, 0% of their adolescent participants meet the diagnostic criteria for a specific phobia. In the study by Salazar et al. (2015), 62% of their participants, 7.5 years old and younger, met diagnostic criteria for specific phobia, but the participants older than 7.5 years old met only 44.6% of the time. These findings suggest that age may play a significant role in diagnosing specific phobia in individuals with ASD.

In addition to the elevated prevalence rates of specific phobias in children and adolescents with ASD, research suggests that this population may also be more likely to experience odd or unusual fears (Mayes, Calhoun et al., 2013). Mayes, Calhoun et al. (2013) assessed a sample of 1033 children and adolescents (ages 1–16) with ASD for fears and specific phobias. Results from this study indicated that more than half of the sample experienced significant fears or phobias, including 41% that endorsed odd or unusual fears (Mayes, Calhoun

et al., 2013). In comparison, unusual fears were present in 0–5% of children and adolescents without ASD (Mayes, Calhoun et al., 2013). Of the 421 participants who endorsed unusual fears, there were 92 fears listed by this portion of the sample (Mayes, Calhoun et al., 2013). In the portion of the children and adolescents that endorsed unusual fears, more than half of these participants reported fears of mechanical things, weather, and/or heights (Mayes, Calhoun et al., 2013). Results from this study also revealed that the most common specific unusual fear was of toilets but stated that the most common category for the unusual fears was related to the fear of mechanical objects (Mayes, Calhoun et al., 2013). The combination of the higher prevalence rates and the increase in unusual fears in this population seems to support the theory that the anxiety experienced in individuals with ASD may be unique to that population. Mayes, Calhoun et al. (2013) suggested that the high percentage of unusual fears in this population could be closely linked to the sensory difficulties that are common in children and adolescents with ASD. The role of sensory difficulties is discussed further in subsequent chapters.

Social Anxiety Disorder

Social anxiety is another disorder that frequently co-occurs in children and adolescents with ASD. The American Psychiatric Association described social anxiety disorder with the following statement:

A person with social anxiety disorder has significant anxiety and discomfort about being embarrassed, humiliated, rejected or looked down on in social interactions. People with this disorder will try to avoid the situation or endure it with great anxiety. Common examples are extreme fear of public speaking, meeting new people or eating/drinking in public. The fear or anxiety causes problems with daily functioning and lasts at least six

months. (American Psychiatric Association, 2021, Social Anxiety Disorder section, para. 1)

The *DSM-5* indicates that when diagnosing social anxiety disorder in children, one of the requirements is that the child must experience anxiety or fear in their interactions with other peers and not just during interactions with adults (American Psychiatric Association, 2013a). The *DSM-5* also reports that the 12-month prevalence rate for children and adolescents in the general population is around 7% and typically decreases with age (American Psychiatric Association, 2013a). In the general population, social anxiety disorder is more frequently diagnosed in females than in males by ratios ranging anywhere between 1.5 to 2.2 (American Psychiatric Association, 2013a). Concerning development and course, the *DSM-5* (American Psychiatric Association, 2013a) states that the “median age at onset of social anxiety disorder in the United States is 13 years, and 75% of individuals have an age at onset between 8 and 15 years” (p. 205).

Meta-analysis studies that examine the prevalence rates of social anxiety disorder in children and adolescents with ASD vary in their results. In the meta-analysis conducted by van Steensel et al. (2011), the authors found that the prevalence rates of social anxiety disorder in children and adolescents with ASD were 17%. In another meta-analysis, Hollocks et al. (2018) critically reviewed 12 studies and estimated the lifetime prevalence rate of social anxiety in children and adolescents with ASD to be approximately 20%. Finally, Kerns, Renno, Storch, et al. (2017) examined 12 studies and found that the prevalence rate of social anxiety in children and adolescents with ASD was approximately 17%.

While the prevalence rate of social anxiety disorder in ASD is not the most prevalent among the anxiety disorders according to the available meta-analysis studies, it is, however, one of the most difficult to differentiate from ASD. Briot et al. (2020) stated, “Recognition of

symptoms of social anxiety may be difficult among individuals with autism spectrum disorders because of overlap between social anxiety and autistic symptomatology” (p. 710). Due to the similar nature of these disorders, ASD is included in the list of differential diagnoses in the social anxiety disorder section of the *DSM-5* (American Psychiatric Association, 2013a). In the Differential Diagnosis section of the *DSM-5*, it states:

Social anxiety and social communication deficits are hallmarks of autism spectrum disorder. Individuals with social anxiety disorder typically have adequate age-appropriate social relationships and social communication capacity, although they may appear to have impairment in these areas when first interacting with unfamiliar peers or adults. (American Psychiatric Association, 2013a, p. 207)

While the *DSM-5* acknowledges the similarities between social anxiety disorder and ASD, it specifies that neurotypical individuals with social anxiety disorder have more age-appropriate social capacities than individuals with ASD. It is often difficult to distinguish whether an individual’s social capacities are impacted by the anxiety symptoms experienced in social anxiety disorder or if their social capacities are impacted by the social deficits associated with ASD. While these similarities can make it difficult for practitioners to differentiate between social anxiety disorder and ASD when trying to assign diagnoses, these similarities can make it even more challenging for practitioners trying to determine whether an individual with ASD also has a comorbid diagnosis of social anxiety disorder. Kreiser and White (2014) described this relationship between social anxiety and ASD as a “bidirectional, mutually exacerbating relationship” (p. 19). Kreiser and White (2014) explained that social anxiety symptoms can impact social deficits and vice versa. This means that the presence of social anxiety can further exacerbate the social deficits present in ASD, and in turn, the social deficits present in ASD can

contribute to increasing social anxiety symptoms. This mutually exacerbating relationship can make social relationships very challenging for individuals with comorbid social anxiety and ASD.

In their meta-analysis, van Steensel et al. (2011) noted that social anxiety in children and adolescents with ASD increases with age and IQ, which means that older adolescents with higher IQs may be more impacted by social anxiety. In contrast to this finding, the study by Varela et al. (2019) found that IQ did not play a significant role in their sample and concluded that utilizing IQ to predict or generalize symptom clusters in this population may yield inaccurate results. Varela et al. (2019) explained that adolescents with ASD with IQ scores that fall below 70 still experience social evaluations in their environments, which may produce symptoms of social anxiety that overwhelm their ability to cope adaptively. Instead, Varela et al. (2019) suggested that evaluating the individual's level of insight into their social functioning is a more accurate predictor for this population as IQ does not define or control insight. Results from their study supported the notion that social anxiety increases with age in this population and noted that this is likely because social insight increases during that stage of development (Varela et al., 2019).

In the meta-analysis by Kerns, Renno, Storch, et al. (2017), the prevalence rates of comorbid social anxiety with ASD varied significantly from 4% to 29.2%. When examining these rates, Kerns, Renno, Storch, et al. (2017) hypothesized the discrepancies in these studies were partly due to the overlap in symptomatology and how this influenced how the symptoms were labeled, interpreted, and coded. It was also hypothesized that these factors could be producing lower levels of comorbid prevalence rates in this population (Kerns, Renno, Storch, et al., 2017). Other researchers, such as Kreiser and White (2014), have also questioned the validity of the current prevalence rates of social anxiety disorder in children and adolescents with ASD.

Kreiser and White (2014) cited “psychometric soundness of measures” (p. 23) as their main reason for concern and specifically questioned the “diagnostic sensitivity of existing measures” (p. 18) when using these measures to assess social anxiety symptoms in individuals with ASD. Concerns with the validity of assessment measures and screening tools for assessing anxiety symptoms in children and adolescents with ASD are mentioned throughout the literature. These concerns are analyzed further in subsequent chapters.

Generalized Anxiety Disorder

Another anxiety disorder that has significant comorbidity rates in children and adolescents with ASD is generalized anxiety disorder. The American Psychiatric Association describes generalized anxiety disorder as the following:

Generalized anxiety disorder involves persistent and excessive worry that interferes with daily activities. This ongoing worry and tension may be accompanied by physical symptoms, such as restlessness, feeling on edge or easily fatigued, difficulty concentrating, muscle tension or problems sleeping. Often the worries focus on everyday things such as job responsibilities, family health or minor matters such as chores, car repairs, or appointments. (American Psychiatric Association, 2021, Generalized Anxiety Disorder section, para. 1)

For the general population, the *DSM-5* indicates that the 12-month prevalence rate for generalized anxiety disorder in adolescents is 0.9%, and the lifetime prevalence rate is 9% (American Psychiatric Association, 2013a). The *DSM-5* also states that the average age of onset is higher in generalized anxiety disorder than in other anxiety disorders and indicates that females are twice as likely to experience generalized anxiety disorder than males (American Psychiatric Association, 2013a). For children and adolescents who do experience generalized

anxiety disorder, their worries typically revolve around their competence or the quality of their performance in different settings (American Psychiatric Association, 2013a). This may result in perfectionistic tendencies and a constant need for reassurance about their performance (American Psychiatric Association, 2013a).

Regarding prevalence rates of generalized anxiety disorder in children and adolescents with ASD, a meta-analysis by Hollocks et al. (2018) examined the lifetime prevalence rates in this population. This study's results showed that this population's overall lifetime prevalence rate was 26% (Hollocks et al., 2018). In this study, the prevalence rates of the individual studies varied significantly and ranged from 16% to 41% (Hollocks et al., 2018). Another meta-analysis by van Steensel et al. (2011) examined 15 studies that produced prevalence rates for this population. The overall prevalence rate from this meta-analysis was 15.4%, and the prevalence rates from the included individual studies ranged from 1.2% to 45.2% (van Steensel et al., 2011). Another meta-analysis by Kerns, Renno, Storch, et al. (2017) examined 12 studies that provided generalized anxiety disorder prevalence rates in children and adolescents with ASD. From this meta-analysis, Kerns, Renno, Storch, et al. (2017) found that the overall prevalence rate was 15%, which was similar to the meta-analysis by van Steensel et al. (2011). The individual studies' prevalence rates in this meta-analysis also varied significantly, ranging from 0% to 66.5% (Kerns, Renno, Storch, et al., 2017).

The level of variability in the prevalence rates that are used in these meta-analysis studies warrants further investigation. Due to the 66.5% discrepancy in the generalized anxiety disorder prevalence rates in the meta-analyses by Kerns, Renno, Storch, et al. (2017), they suggested that this variation could be due to factors such as assessment methods and the cognitive functioning levels of the participants used in each of the samples. Concerning the assessment methods,

Kerns, Renno, Storch, et al. (2017) indicated that some of the studies that they used in their meta-analysis utilized parent reports as part of their data collection. Gjevik et al. (2010) utilized only parent reports and found that none of the parents in their sample endorsed generalized anxiety symptoms in their child or adolescent with ASD. Using parent reports as the only source of data collection in studies has been scrutinized when assessing emotional or internal processes such as anxiety in this population (Kerns, Renno, Storch, et al., 2017). It is difficult for parents to interpret these internal processes, which can lead to varied results. According to Kerns, Renno, Storch, et al. (2017), the other potential cause for the variability in their results was the variation of cognitive functioning levels in their studies. They found that generalized anxiety symptoms in the “low-functioning” groups ($IQ < 70$) were significantly less prevalent than in the “high-functioning” groups ($IQ > 70$). The meta-analysis by van Steensel et al.’s (2011) did not find IQ as a moderating effect for generalized anxiety disorder but found that studies with a higher mean age had higher prevalence rates of generalized anxiety disorder in this population. In contrast to the findings by van Steensel et al. (2011), a study by Varela et al. (2019) identified patterns of generalized and social anxiety for children and adolescents with ASD across different developmental stages. Varela et al. (2019) intended to identify whether the patterns for children and adolescents with ASD were similar to the neurotypical patterns. For this study, Varela et al. (2019) utilized archival data from an autism center in a hospital in the southeast United States. The data used came from evaluations conducted at the clinic between June 2006 and June 2016. Since this study examined developmental patterns, the sample was split into 6–11-year-old children and 12–18-year-old adolescents. Altogether, there were 354 participants, including 294 participants in the 6–11-year-old group and 60 participants in the 12–18-year-old group. Concerning the sex of the participants, there were 284 males and 70 females. It is also important

to note that the sample had a mean IQ of 67.87, and 66.13% had an IQ of 70 or above. Each participant was administered the Behavioral Assessment System for Children-Second Edition (BASC-2), and results showed that 16.78% of the 6–11-year-old group and 25% of the 12–18-year-old group endorsed clinically elevated symptoms on the anxiety subscale of this measure. Varela et al. (2019) found a positive correlation between age and overall anxiety level for this population, which supports the findings of the other studies that have been discussed. Results also showed that the older group endorsed more social anxiety symptoms than the younger group, and the younger group endorsed more generalized anxiety symptoms than the older group. Finally, Varela et al. (2019) stated that their findings suggest children and adolescents with ASD experience specific types of worries across different developmental stages that closely resemble the pattern observed in neurotypical children and adolescents. Children and adolescents with ASD have more general worries that align more with generalized anxiety disorder in the 6–11-year-old group, and then those worries tend to shift to more social evaluation worries that align more with social anxiety disorder in the 12–18-year-old group (Varela et al., 2019). Overall, generalized anxiety disorder continues to have high comorbidity rates in children and adolescents with ASD.

Separation Anxiety Disorder

Separation anxiety is the next disorder examined. The American Psychiatric Association provides the following statement that describes separation anxiety disorder:

A person with separation anxiety disorder is excessively fearful or anxious about separation from those with whom he or she is attached. The feeling is beyond what is appropriate for the person's age, persists (at least four weeks in children and six months in adults), and causes problems functioning. A person with separation anxiety disorder

may be persistently worried about losing the person closest to him or her, may be reluctant or refuse to go out or sleep away from home or without that person, or may experience nightmares about separation. Physical symptoms of distress often develop in childhood, but symptoms can carry through adulthood. (American Psychiatric Association, 2021, Separation Anxiety Disorder section, para. 1)

In the United States general population, the 6-to-12-month prevalence rate for separation anxiety disorder in children is approximately 4% (American Psychiatric Association, 2013a). The 12-month prevalence rate in adolescents was approximately 1.6% (American Psychiatric Association, 2013a). According to the *DSM-5* (American Psychiatric Association, 2013a), separation anxiety is the most prevalent anxiety disorder in children under 12 years old and is equally prevalent among males and females. Concerning development and course, separation anxiety disorder typically develops in childhood, but symptoms typically decrease as the child progresses toward adolescence (American Psychiatric Association, 2013a). There are instances where separation anxiety symptoms could persist into later adolescence and adulthood, but this is rare as the 12-month prevalence rate for adults is between 0.9% and 1.9% (American Psychiatric Association, 2013a). According to the *DSM-5* (American Psychiatric Association, 2013a), when assessing for separation anxiety disorder, it is important to remember that neurotypical children experience some degree of separation anxiety as part of typical early development. Around the age of one, it is developmentally appropriate for children to experience separation anxiety when removed from the presence of their primary attachment figure(s) or in the presence of strangers (American Psychiatric Association, 2013a). It is important for practitioners to be aware of these development stages when assessing anxiety in children and adolescents. If separated from their attachment figures, neurotypical children may experience secondary symptoms such as sadness,

apathy, difficulties with attention and concentration, social withdrawal, school refusal, and academic struggles. In more acute cases, anger or aggression may occur if the individual is faced with separation from their attachment figure (American Psychiatric Association, 2013a).

When examining the prevalence rates of separation anxiety disorder in children and adolescents with ASD, the meta-analysis conducted by van Steensel et al. (2011) found that the prevalence rate for this population was 9.0%. The meta-analysis by Kerns, Renno, Storch, et al. (2017) also found that the comorbidity rate for separation anxiety disorder and ASD in children and adolescents was also 9.0%. The last meta-analysis by Hollocks et al. (2018) found that the lifetime prevalence rate of separation anxiety disorder in this population was 21%. It is important to note that in all three of these meta-analysis studies the disparity between the prevalence rates in the individual studies that were used was much less severe than the other anxiety disorders that have been addressed up to this point (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). Despite the substantial prevalence rates of separation anxiety disorder in children and adolescents with ASD, research on this comorbidity is limited. From the available research, the meta-analysis by van Steensel et al. (2011) suggested that age and IQ have moderating effects on separation anxiety symptoms in this population. Results indicated that samples with a lower mean age had higher prevalence rates of separation anxiety symptoms, and samples with a higher mean IQ were associated with higher rates of separation anxiety symptoms. Sharpley et al. (2020) wanted to closely examine the differences between social anxiety symptoms and separation anxiety symptoms in a sample of children and adolescents with ASD and a sample without ASD. This study used a sample of 167 males (ages 6–17 years old) from Southeast Queensland, Australia. This sample consisted of 117 males with ASD and 50 males without ASD; all of the study participants had an IQ of 70 or above. When comparing

these two groups, Sharpley et al. (2020) found that the ASD group experienced significantly higher levels of social anxiety symptoms and separation anxiety symptoms than the non-ASD group. Results also indicated that the ASD group experienced a gradual decrease in separation anxiety symptoms as they increased in age, with the most significant reduction occurring at 12–13 years old. While Sharpley et al. (2020) were unable to provide a reason for this reduction of symptoms in the 12–13-year-old group, they hypothesized that the increase in testosterone during puberty may have an impact on separation anxiety symptoms. From these available results, it appears that age and IQ play a role in the development and course of separation anxiety disorder in children and adolescents with ASD. Results also support the idea that children and adolescents with ASD may experience more severe separation anxiety symptoms when compared to non-ASD samples. Due to limited research on this topic, this area still warrants further investigation.

Agoraphobia

Agoraphobia is another anxiety disorder that has been linked to high comorbidity rates in children and adolescents with ASD. When describing agoraphobia, the American Psychiatric Association made the following statement:

Agoraphobia is the fear of being in situations where escape may be difficult or embarrassing, or help might not be available in the event of panic symptoms. The fear is out of proportion to the actual situation and lasts generally six months or more and causes problems in functioning. The individual actively avoids the situation, requires a companion, or endures with intense fear or anxiety. Untreated agoraphobia can become so serious that a person may be unable to leave the house. A person can only be diagnosed with agoraphobia if the fear is intensely upsetting, or if it significantly

interferes with normal daily activities. (American Psychiatric Association, 2021, Agoraphobia section, para. 1)

The prevalence rate for agoraphobia in the general population in the United States is approximately 1.7% for adolescents and adults (American Psychiatric Association, 2013a). The *DSM-5* (American Psychiatric Association, 2013a) indicates it is rare for agoraphobia to develop in childhood and states that initial onset typically occurs in late adolescence and early adulthood. Prevalence rates in the general population decrease with age groups, and the prevalence rate for individuals over 65 years old is 0.4% (American Psychiatric Association, 2013a). Agoraphobia is also twice as likely in females than in males in the general population (American Psychiatric Association, 2013a). Regarding development and course, the *DSM-5* (American Psychiatric Association, 2013a) indicates that two-thirds of the general population with agoraphobia had an initial onset before the age of 35, and the mean age for the initial onset of this disorder is 17. It is common for panic attacks or panic disorder to occur before the onset of agoraphobia, with 30% of the community sample and 50% of the clinical sample occurring before the onset of agoraphobia (American Psychiatric Association, 2013a). Agoraphobia is typically a chronic disorder that rarely goes into remission without treatment. Even with treatment, complete remission of agoraphobia is still rare, and relapse is common in more acute cases (American Psychiatric Association, 2013a). Additionally, the *DSM-5* (American Psychiatric Association, 2013a) states that long-term difficulties with agoraphobia are associated with an elevated risk for depressive and substance abuse disorders.

Meta-analysis studies show that the prevalence rates for agoraphobia in children and adolescents with ASD are much higher than in the general public. The meta-analysis by van Steensel et al. (2011) showed that this population's prevalence rate was 16.6%. In their meta-

analysis, Kerns, Renno, Storch, et al. (2017) found that the prevalence rate of agoraphobia in children and adolescents with ASD was 17%. Additionally, the meta-analysis by Hollocks et al. (2018) showed that the prevalence rate in their study was 18%. Aside from the prevalence rates, the meta-analysis studies did not provide much additional information about agoraphobia, and no conclusions could be made with respect to age and IQ from these studies. In a study by Salazar et al. (2015), they were able to draw conclusions about moderating factors from their results. Results from this study indicated that higher prevalence rates of agoraphobia were associated with increased age of the participants. Salazar et al. (2015) also found that the parental reports endorsed high rates of anticipatory anxiety and avoidance behaviors, particularly in settings such as public transportation and loud shops. Salazar et al. (2015) theorized that these highly endorsed areas could be linked to the sensory sensitivities commonly present in children and adolescents with ASD. These settings are known to have high levels of sensory stimuli that may be extremely overwhelming and aversive to this population. This is still an area that needs further exploration.

Panic Disorder

The last anxiety disorder that has notable co-occurrence rates in children and adolescents with ASD is panic disorder. When explaining panic disorder, the American Psychiatric Association (2021) stated, “The core symptom of panic disorder is recurrent panic attacks, an overwhelming combination of physical and psychological distress” (Panic Disorder section, para.

1). The American Psychiatric Association also stated the following about the symptoms:

Because symptoms are so severe, many people who experience a panic attack may believe they are having a heart attack or other life-threatening illness and may go to a hospital ER. Panic attacks may be expected, such as a response to a feared object, or

unexpected, apparently occurring for no reason. (American Psychiatric Association, 2021, Panic Disorder section, para. 3)

According to the *DSM-5* (American Psychiatric Association, 2013a), the prevalence rate of panic disorder in the general population in the United States is between 2%-3% in older adolescents and adults, and females are twice as likely to experience panic disorder than men. The average age of onset for panic disorder is between 20–24 years old, and typically has a chronic trajectory if left untreated (American Psychiatric Association, 2013a). Panic disorder is very rare in children, but individuals diagnosed with it often report elevated fears that date back to their childhood. There is also a strong correlation between panic disorder and other anxiety disorders, as well as depressive disorders and substance use disorders (American Psychiatric Association, 2013a). The *DSM-5* (American Psychiatric Association, 2013a) also indicates that cultural factors may play a significant role in the prevalence rates of panic disorders, noting that other cultures may have cultural syndromes that may encapsulate all or some of the panic disorder criteria. It is also noted that the sources of the panic symptoms may differ based on the cultural and functional impairments that may also vary (American Psychiatric Association, 2013a).

Regarding the prevalence rates of panic disorder in children and adolescents with ASD, meta-analysis data reveal that the comorbidity rates in this population are similar to the rates of the general population (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). The meta-analysis by van Steensel et al. (2011) found that the prevalence rate of panic disorder in this population was 1.8%. Kerns, Renno, Storch, et al. (2017) obtained similar findings in their meta-analysis and reported the prevalence rate to be 2.0%. In the study by Hollocks et al. (2018), the lifetime prevalence rate for panic disorder was reported to be 18%. Notably, this meta-analysis contained an adult sample, which is most likely the reason for their

higher lifetime rates. Like the other comorbid anxiety disorders with lower prevalence rates in this population, the research in this area is very limited. Many studies that contain statistics about comorbidity rates state the prevalence rate for panic disorder and do not offer any further information. The meta-analysis studies were unable to provide any correlation between age and IQ like in other anxiety disorders (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). It may be that the symptoms of anxiety in children and adolescents with ASD are better accounted for by other anxiety disorders. This is also an area that warrants further investigation.

Obsessive-Compulsive Disorder

When the *DSM-5* (American Psychiatric Association, 2013a) was released, OCD was removed from the *Anxiety Disorders* section and placed in the *Obsessive-Compulsive and Related Disorders* section. While no longer classified as an anxiety disorder, OCD is still discussed in this clinical research project due to its close relation to anxiety disorders, its close ties to ASD in symptomatology, and the depth of the comorbidity research conducted in this area. The American Psychiatric Association defines OCD as:

A disorder in which people have recurring, unwanted thoughts, ideas, or sensations (obsessions) that make them feel driven to do something repetitively (compulsions). The repetitive behaviors, such as hand washing, checking on things or cleaning, can significantly interfere with a person's daily activities and social interactions. (American Psychiatric Association, 2021, Obsessive-compulsive Disorder section, para. 1)

The *DSM-5* (American Psychiatric Association, 2013a) indicates that the 12-month prevalence rate for OCD in the United States is 1.2%, and international rates are between 1.2%–1.8%. According to the *DSM-5* (American Psychiatric Association, 2013a), the development and

course of OCD are rather diverse regarding age and sex. While the mean age of onset for OCD in the United States is 19.5 years old, a significant portion (25%) of the cases have an onset before 14 years old, and onset after 35 years old is rare (American Psychiatric Association, 2013a). Regarding sex differences, females are more affected in adulthood, but males are more affected in childhood (American Psychiatric Association, 2013a). Approximately one-quarter of males who experience OCD have their onset of symptoms before they are 10 years old (American Psychiatric Association, 2013a). The *DSM-5* (American Psychiatric Association, 2013a) reports that the onset of symptoms for OCD is generally gradual and is usually chronic across the lifespan if left untreated. Only 40% of children diagnosed with OCD experience remission by adulthood (American Psychiatric Association, 2013a).

Meta-analysis data show that the co-occurrence rates of OCD in children and adolescents with ASD are quite high (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). The meta-analysis by van Steensel et al. (2011) found that the prevalence rate for OCD in this population was 17.4%. Similarly, the meta-analysis by Kerns, Renno, Storch, et al. (2017) found that their results indicated that the prevalence rate of OCD was 17%. Hollocks et al.'s (2018) study produced a prevalence rate of 22% for OCD in this population. Concerning moderating factors in these studies, van Steensel et al. (2011) found a correlation between higher IQ levels and higher rates of OCD. They also found that the prevalence rates were higher in studies with lower mean age.

Similar to the findings in other anxiety disorders, meta-analysis data showed high levels of variation in the prevalence rates of OCD in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). In the study by van Steensel et al. (2011), the prevalence rates for OCD in children and adolescents with ASD varied from 2.6% to 37.2%.

Additionally, the prevalence rates of OCD in the study by Kerns, Renno, Storch, et al. (2017) varied from 0% to 57%. When investigating the cause of this significant variation, van Steensel et al. (2011) theorized that this was due to an overlap in diagnostic symptomatology. Concerning this overlapping symptomatology, van Steensel et al. (2011) stated, “Clearly, there is diagnostic overlap between the anxiety subtypes and the criteria for ASD, especially between ASD and OCD, and ASD and social anxiety disorder” (p. 310). Postorino et al. (2017) specifically examined the co-occurrence of anxiety disorders and OCD in individuals with ASD. In this study, Postorino et al. (2017) also mentioned the diagnostic overlap between these disorders and explained “expressions of anxiety such as social withdrawal and ritualistic behaviors can be superficially similar to the core social deficits of ASD making the differentiation of these conditions difficult” (p. 3). The diagnostic overlap between ASD and OCD poses significant challenges to the research in this area. When filling out diagnostic questionnaires/assessments or participating in diagnostic interviews, it can be difficult for the child or adolescent to differentiate between these symptoms, and it can also be challenging for the caregivers to accurately report on the subjective mental experience of the child or adolescent. Kerns, Renno, Storch, et al. (2017) stated that due to these challenges, researchers will apply modifications to diagnostic criteria for their study to be completed, which can also impact the variation in the prevalence rates in this population. It is also stated throughout the literature that one of the main reasons for variation in prevalence rates is because studies are using assessment measures that have not been designed for developed for this population (Kerns, Renno, Storch, et al., 2017; Postorino et al., 2017; van Steensel et al., 2011). These issues with assessment validity for the ASD population are explored further in subsequent chapters.

When attempting to differentiate between the repetitive behaviors in ASD and OCD, Postorino et al. (2017) stated that looking at the function of the behaviors is helpful. In OCD, repetitive behaviors are compulsions meant to satisfy intrusive obsessions and, in turn, either satisfy the individual's anxiety or provide some relief from the anxiety. For individuals with OCD, these repetitive behaviors are often associated with distress and are unwanted and vexing (Postorino et al., 2017). For individuals with ASD, repetitive behaviors are more associated with stereotyped motor behaviors. These repetitive behaviors often vary in the type of stereotyped motor behavior and the severity of the behaviors. Unlike OCD, these repetitive behaviors are not always linked to distress and can be associated with pleasure or more positive feelings. It should be noted that similar to OCD, these repetitive behaviors in ASD can also be time-consuming, and children and adolescents with ASD can have adverse reactions if these repetitive behaviors are interrupted (Postorino et al., 2017).

Similar to other areas of ASD research, studies on ASD and OCD comorbidity are limited. From the available research, Ruta et al. (2009) found that children and adolescents with ASD were more likely to experience hoarding obsessions and hoarding, repeating, and ordering compulsions when compared to a group without ASD. Ruta et al. (2009) also found that individuals diagnosed with OCD without ASD were likelier to experience obsessions related to contamination and aggression and compulsions related to checking. Martin et al. (2020) also explored co-occurring OCD in children and adolescents with ASD. In this study, they utilized an ASD with OCD group, an ASD without OCD group, and an OCD without ASD group to compare and contrast their findings. Results from this study found that children and adolescents from the ASD and OCD group had lower scores on psychosocial functioning measures when compared to the other two comparison groups. Results also showed that the ASD with OCD

group was more likely to receive medication in combination with cognitive behavioral therapy (CBT) treatment, and this group was also more likely to receive treatment for longer periods than the other comparison groups. Compared to the OCD without ASD group, the ASD with OCD group made slower progress in treatment and were more likely to require longer-term care.

Additionally, Martin et al. (2020) also stated that they believe OCD is likely underdiagnosed in children and adolescents with ASD. They stated, “it is possible that OCD is underdiagnosed in youth with ASD in routine clinical practice because either ASD-associated problems overshadow OCD symptoms, or OCD symptoms are viewed as part of ASD themselves” (Martin et al., 2020, p. 1608). This is an area of study that requires further investigation.

CHAPTER III: HOW DO SYMPTOMS OF ANXIETY MANIFEST IN CHILDREN AND ADOLESCENTS WITH ASD?

While the last chapter established the significant prevalence of anxiety symptoms in children and adolescents with ASD, this chapter explores how symptoms of anxiety manifest in this population. Clearly defining and accurately describing how anxiety manifests in children and adolescents with ASD is difficult due to the heterogeneity that exists across this population (Kerns, Renno, Storch, et al., 2017; Masi et al., 2017; Mottron & Bzdok, 2020; Postorino et al., 2017; van Steensel et al., 2011). While heterogeneity in this population has been observed throughout history, current arguments suggest that the transition to the autism spectrum model in the *DSM-5* may have played a significant role in the increase of heterogeneity in this population (Mottron & Bzdok, 2020). When discussing this transition to the autism spectrum model and how it impacted the degree of heterogeneity in this population, Mottron and Bzdok (2020) stated “Combining nonspecific social and repetitive categorical criteria with four “open” specifiers (levels of intelligence, language, severity, and comorbidity), as well as all their possible combinations, can result in a vast array of ASD presentations” (p. 3180). In addition to the shift to the autism spectrum model, research has indicated that the broad heterogeneity in this population is “a function of the multiple genes involved, the myriad of environmental factors impacting the developmental course of symptom expression, and the co-occurrence of medical and mental health dysfunctions in ASDs” (Masi et al., 2017, p. 187).

Research in this area has been significantly impacted by this heterogeneity, which has made it difficult to understand the role of anxiety in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; Masi et al., 2017; Mottron & Bzdok, 2020; Postorino et al., 2017; van Steensel et al., 2011). Literature in this area has identified a number of factors that have

contributed to this variation and, in turn, have had considerable influence on our current understanding of how anxiety manifests in this population and how it is conceptualized. Because these factors influence how anxiety presents in this population, they can also be considered risk factors.

Factors Impacting How Anxiety Manifests in Children and Adolescents with ASD.

The following sections further explore these factors and how these factors influence the manifestation and presentation of anxiety in children and adolescents with ASD.

Sex Differences

One of the factors that has a significant impact on the research in this area is sex differences. In regard to sex differences in children and adolescents with ASD, current data show that ASD is 4.3 times more prevalent in males than in females (Maenner et al., 2020). While studies have consistently reported higher prevalence rate in males, there is some research suggesting that the prevalence rate for females may not be accurate. Accardo et al., (2022) proposed that the prevalence rate for females may actually be higher than is currently reported because females are more likely to engage in masking or camouflaging their autistic symptoms. A review on social camouflaging in females with ASD conducted by Tubío-Fungueiriño et al., (2020) reported that most of the females who engage in this behavior try to do so for adaptive purposes; however, it frequently leads to negative symptoms such as increased anxiety and depression. This is a variable that is difficult to study and further impacts the prevalence rate of ASD and the prevalence rate of anxiety in this population.

When examining the prevalence rate of anxiety in typically developing children, current research suggests that females have higher rates of anxiety disorders than males (Koet et al., 2022; Steinsbekk et al., 2021). Research that examines the prevalence rates of anxiety disorders

in children and adolescents with ASD has had mixed results. Some studies have shown that females with ASD have higher rates of anxiety (Sedgewick et al., 2020; So et al., 2021; Vadukapuram et al., 2022), while other studies have shown that there are no differences in anxiety disorder prevalence rates among males and females with ASD (Margari et al., 2019; Proserpi et al., 2021; van Steensel et al., 2014). In response to these mixed results, van Steensel et al. (2014) suggested that very little is known about anxiety in females with ASD because males are diagnosed with ASD at a significantly higher rate and are the subject of the majority of the research in this area. Other research suggests that age may also play a role when examining gender differences in children and adolescents with ASD. Salazar et al. (2015) and So et al. (2021) made sure to include a large portion of females in their samples so they could be able to determine if the sex of the child or adolescent had any impact on their anxiety symptoms. Salazar et al. (2015) assessed 101 children (44 participants were female) aged 4.5–9.8 years diagnosed with ASD.

In this particular study, the majority of the results between males and females were similar concerning anxiety. However, there were higher rates of attention deficit/hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD) in males (Salazar et al., 2015). So et al. (2021) assessed 189 adolescents with ASD (64 participants were female) ages 12–18 years old. Findings from this study showed that these adolescent female participants struggled more with anxiety symptoms when compared to adolescent males (So et al., 2021). Additionally, So et al. (2021) and Vadukapuram et al. (2022) examined the differences in the psychiatric comorbidities of adolescent males and females with ASD who had been admitted to inpatient psychiatric units. Results from these studies found that the rates of anxiety disorders were higher in female patients when compared to male patients. When examined together, these findings

suggest that the sex of the individual may impact the prevalence rates of anxiety in children and adolescents with ASD, but this factor may be moderated by age. Overall, there is enough evidence to conclude that the sex of the child or adolescent with ASD significantly influences the manifestation of anxiety in this population. Further investigation of the anxiety rates in child and adolescent females with ASD is needed to continue to develop conclusions in this area of research.

Age

While age is an important variable in many disorders, it may be one of the most important variables in ASD, particularly in regard to early identification of the disorder. Zwaigenbaum et al., (2013) stated “Earlier identification and diagnosis of autism spectrum disorders (ASDs) can improve opportunities for children to benefit from intervention and lessen the burden on concerned parents” (p. 133). Due to the fact that early identification leads to better outcomes, there is a significant sector of ASD research dedicated to identifying early warning signs of ASD symptoms. While the research varies, some studies have identified signs of ASD in babies as young as six months old; however, most studies have found that overt behavioral signs are not generally present until after six months of age (Zwaigenbaum et al., 2019). While research has been able to identify some early signs, Zwaigenbaum et al. (2019) noted “Symptoms in the core domains of ASD usually emerge between 12 and 24 months” (p. 425). In regard to anxiety, research also suggests that early identification and intervention are key to better outcomes. In a review about childhood anxiety, Griffiths and Fazel (2016) stated “Early detection and treatment of childhood anxiety disorders can prevent significant impairment” (p. 18). This review also reported that approximately 75% of anxiety disorders have signs that began in childhood and untreated anxiety disorders in this population significantly increase the chances

of developing depression or chronic anxiety in adulthood (Griffiths & Fazel, 2016). With the importance of early identification in both of these disorders, and the increased risk of anxiety in children and adolescents with ASD, it is imperative this population is screened early for anxiety treatment and either receive treatment when indicated or continue to be monitored for signs of anxiety.

In neurotypical populations, research has shown that children and adolescents experience anxiety differently as they progress through the different developmental stages (Varela et al., 2019; Weems & Costa, 2005). This research suggests that overall anxiety symptoms and the intensity of anxiety symptoms typically decrease throughout developmental stages; however, there have been correlations between specific anxiety symptoms and certain developmental stages (Varela et al., 2019; Weems & Costa, 2005). Weems and Costa (2005) found that separation anxiety symptoms were predominant in the 6–9 years old group, fears of death and potential danger were more prominent in the 10–13 years old group, and symptoms of social anxiety were more prominent in the 14–17 years old group. Results from this study also suggested that symptoms of social anxiety were most severe in older youth and noted that the intensity of these symptoms was comparable to the intensity of the anxiety in the younger children (Weems & Costa, 2005).

The research about the relationship between age and anxiety symptom in children and adolescents with ASD suggests that age does play a moderating role in this population (Davis et al., 2011; van Steensel et al., 2011; Varela et al., 2019; Vasa & Mazurek, 2015). Davis et al. (2011) found evidence that individuals with ASD experience different anxiety levels across their lifespan. For this study, a sample of 131 participants with autistic disorder was divided into age groups that spanned across the lifespan. The age groups were divided into the toddler group

(ages 17–36 months), the child group (ages 3–16 years old), the young adult group (ages 20–48 years old), and the adult group (ages 48–65 years old) (Davis et al., 2011). Results from this study indicated that individuals with autistic disorder (now part of the ASD diagnosis) experience increased anxiety from toddlerhood to childhood, then their anxiety levels decrease from childhood to young adulthood, and then increase again from young adulthood to older adulthood (Davis et al., 2011). Studies with samples across the lifespan are rare and the article by Davis et al. (2011) is one of the only studies providing these comparisons across the lifespan.

Other articles have examined specific anxiety disorders in this population and have found correlations between certain anxiety disorders and specific age ranges. In a meta-analysis, van Steensel et al. (2011) found that overall anxiety and generalized anxiety disorder prevalence rates increased with age. They also found that OCD and separation anxiety disorder prevalence rates were more associated with studies with lower mean ages (van Steensel et al., 2011). Varela et al. (2019) found that older children (ages 12–18 years old) were more likely to experience social anxiety symptoms, and younger children (ages 6–11 years old) were more likely to experience generalized anxiety symptoms. This study was limited to just social anxiety disorder and generalized anxiety disorder, but it provides evidence that age may correlate with the type of anxiety experienced in this population (Varela et al., 2019). Additionally, it was noted in this study that social anxiety symptoms and generalized anxiety symptoms were correlated with different developmental stages. This correlation was particularly significant with social anxiety, which is known to increase as social understanding increases (Varela et al., 2019).

Providing more evidence that younger children with ASD are more likely to experience higher rates of anxiety, Salazar et al. (2015) conducted a study examining co-occurring psychiatric disorders in preschool and elementary students who were diagnosed with ASD. For

this study, Salazar et al. (2015) assessed 101 children (and their families) aged 4.5–9.8 years from London, England. All of these participants had an ASD diagnosis and the sample consisted of 44 females and 57 males (Salazar et al., 2015). All of the participants were assessed using a full diagnostic assessment that included an IQ measure, an ASD assessment, a receptive language assessment, a semi-structured interview with the parents, and direct observations of the child (Salazar et al., 2015). After these thorough assessments, Salazar et al. (2015) found that 90.5% of their sample also met diagnostic criteria for at least one other psychiatric disorder. The prevalence rate for emotional disorders was 80.0% and the prevalence rate for behavioral disorders was 28.7% (Salazar et al., 2015). The prevalence rates of the co-occurring disorders were generalized anxiety disorder (66.5%), specific phobias (52.7%), social anxiety disorder (15.1%), agoraphobia (18.0%), major depressive disorder (14.6%), ADHD (59.1%), ODD (28.7%), and conduct disorder (2.0%) (Salazar et al., 2015). When further examining these co-occurring disorders, Salazar et al. (2015) found that 75.6% of the sample met criteria for at least two anxiety disorders. Of all the combinations, generalized anxiety disorder and specific phobias were the most common at 24.3% (Salazar et al., 2015). Finally, the researchers found that anxiety disorders were more common in individuals with higher IQ and increased with age. Overall, research suggests that age does play a significant role in how anxiety manifests in children and adolescents with ASD.

Intellectual Functioning

Intellectual functioning is another factor that has been identified in the research to have a significant impact on the way that anxiety manifests in children and adolescents with ASD (Kerns et al., 2020; Mingins et al., 2020; van Steensel et al., 2011). Prevalence studies have estimated that approximately 33%–55% of children and adolescents with ASD also have

comorbid intellectual disability (Charman et al., 2010; Maenner et al., 2020). Charman et al. (2010) found that 55% of their ASD sample met criteria for intellectual disability. Moderate to severe intellectual disability was present in 16% and the other 39% of the sample fell into the mild range of intellectual disability. This study also found that 28% of their sample presented with average intelligence and 3% of the sample had above average intelligence (Charman et al., 2010).

While prevalence data have shown a significant correlation between ASD and intellectual disability, studies on the impact of intellectual functioning on anxiety symptoms in children and adolescents with ASD have produced varying results (Kerns et al., 2020; Mingins et al., 2020; Salazar et al., 2015; van Steensel et al., 2011). Due to the variability of the results in this area of research, Mingins et al. (2020) conducted a meta-analysis with the goal of better defining the relationship between IQ and anxiety symptoms in this population. While discussing this variability in the literature, Mingins et al. (2020) stated “Existing literature presents unclear and contradictory estimates of the relationship between IQ and anxiety in autistic children and often ignores the large proportion of children with comorbid ID” (p. 20). For this meta-analysis, Mingins et al. (2020) applied inclusion and exclusion criteria when reviewing the literature, which produced 49 studies that included 18,430 autistic children. Prior to presenting the findings of their study, Mingins et al. (2020) outlined the limitations mentioned throughout many of the research studies that were included in the meta-analysis. One of the most frequently mentioned limitations was challenges associated with emotional intelligence, specifically alexithymia (Mingins et al., 2020). According to Kinnaird et al. (2019), “alexithymia refers to difficulties in recognizing and distinguishing between different emotions and bodily sensations, difficulties in expressing emotions, a lack of imagination or fantasy life, and thoughts focused on external

rather than internal experience” (p. 80). While alexithymia is not a core diagnostic feature of ASD, the prevalence rates of co-occurring alexithymia in ASD are reported to range from 33.3% to 63% (Kinnaird et al., 2019). These difficulties with emotional recognition and emotional expression can make it difficult to assess the internal experience of children and adolescents with ASD. Due to the challenges associated with expressing and communicating emotions, research studies often need to rely on other-informant reports rather than self-reports when assessing for anxiety symptoms in individuals with ASD. These other-informant reports often rely on observations from external behaviors to draw conclusions about internal states. It is difficult to know the reliability of these informant reports, but it is often the only way to collect data (Kinnaird et al., 2019).

The other major challenge that was highlighted by Mingins et al. (2020) in this meta-analysis was the validity and reliability concerns when using assessments to measure anxiety symptoms in this population. One of the major issues with these anxiety assessments is that many of them have been adapted to ASD using samples that have average to above average cognitive functioning levels (Mingins et al., 2020). Very little research has focused on adapting anxiety measures for children and adolescents with ASD and comorbid intellectual disability (Mingins et al., 2020). Kerns et al. (2020) also noted that many of the assessments used to measure anxiety were not designed for youth with ASD or intellectual disability so using these measures to assess anxiety in children and adolescents with ASD and intellectual disability can be unreliable. The validity and reliability of anxiety assessment measures for children and adolescents with ASD are discussed in further detail in the limitations section of this review.

Overall, the results from the meta-analysis by Mingins et al. (2020) indicated that higher IQ was associated with higher levels of anxiety in children and adolescents with ASD. In the

literature, there are different theories about why higher IQ is linked to higher levels of anxiety in this population. One theory is that a higher IQ is associated with higher levels of cognitive abilities (Kerns & Kendall, 2012). The idea is that a higher IQ is associated with higher-level cognitive functions such as abstract thinking and planning (Salazar et al., 2015). The ability to perform these higher-level cognitive functions would place the individual at a greater risk of experiencing worries related to these functions (Kerns & Kendall, 2012; Salazar et al., 2015). Another theory is that higher IQ is associated with a better ability to self-evaluate, which could lead to increased insight. Increased insight in social situations would theoretically allow an individual to recognize their social deficits when compared to their peers, which could increase their levels of anxiety (Acker et al., 2018). While Mingins et al. (2020) found that children and adolescents with ASD and higher IQs are more likely to experience anxiety symptoms, they also indicated that this group is more likely to have effective coping mechanisms, which is a protective factor.

While the Mingins et al. (2020) meta-analysis provided valuable information about how the levels of anxiety are impacted by IQ, they did not investigate if the type of anxiety was affected by the level of intellectual functioning. In a meta-analysis, van Steensel et al. (2011) examined the moderating effects of IQ on the type of anxiety symptoms experienced in this population. Results from this study were contradictory to the findings from the Mingins et al. (2020) meta-analysis and indicated that children and adolescents with lower IQ scores were more likely to have increased rates of anxiety disorders (van Steensel et al., 2011). Results from this study also showed that lower IQ was associated with higher prevalence rates of social anxiety disorder (van Steensel et al., 2011). Furthermore, higher IQ scores were associated with higher prevalence rates in OCD and separation anxiety disorder (van Steensel et al., 2011). When

examining specific IQ ranges, van Steensel et al. (2011) found that individuals with IQ scores between 70 and 87 had an increased risk for an anxiety disorder. They mentioned this is an area that warrants further investigation as only one study had a sample where the mean IQ score was below 70 (van Steensel et al., 2011). When discussing the correlation between lower IQ scores and higher rates of social anxiety disorder, van Steensel et al. (2011) explained that the lack of studies with mean IQ scores below 70 may have impacted this finding as well. They theorized that the children and adolescents with IQ scores in the 70–87 range may recognize that they are struggling to adapt to their social environments but do not possess the social skills necessary to compensate for their deficits, which may create feelings of social anxiety. Overall, the meta-analysis by van Steensel et al. (2011) provided evidence that there is a correlation between IQ level and the type of anxiety experienced by children and adolescents with ASD.

Kerns et al. (2020) also investigated the impact of intellectual functioning on anxiety symptoms in children and adolescents with ASD. In this study, the sample comprised 75 children with ASD and 52 neurotypical children, all between the ages of 9–13 years and all with varied levels of intellectual functioning. This study was unique because it examined DSM-specific anxiety and OCD symptoms as well as what they termed “distinct” anxiety that is often observed in children and adolescents with ASD and causes significant distress but does not fit into any DSM categories (Kerns et al., 2020). These distinct anxiety fears included fears of change, uncommon phobias, special interest fears, social confusion (social fears unrelated to negative evaluation), and ambiguous compulsive behaviors (Kerns et al., 2020). Results from this study suggested that the ASD group was much more likely to present with a DSM anxiety disorder than the neurotypical group. A DSM anxiety disorder or OCD was present in 52% of the ASD group and only 8% of the neurotypical group. Concerning anxiety symptoms, 69% of the ASD

group presented with clinically significant anxiety symptoms and was divided into 21% who presented with DSM anxiety symptoms only, 17% who presented with distinct anxiety symptoms only, and 31% who presented with both. Specific phobia was the most frequent DSM diagnosis among the ASD group, with 44% of the ASD group meeting criteria, followed by generalized anxiety disorder (15%), separation anxiety disorder (7%), social anxiety disorder (7%), and OCD (4%) (Kerns et al., 2020). Concerning the distinct anxiety symptoms, 48% of the ASD endorsed at least one distinct anxiety symptom that fell into the clinically significant range. Percentages of these distinct fears were divided into the following: fears of change (23%), uncommon phobias (15%), other social fears (8%), special interest fears (7%), and ambiguous compulsive behavior (8%). When investigating the overlap in the DSM anxiety data and the distinct anxiety data in the ASD group, Kerns et al. (2020) found that of the portion of the ASD sample that met the criteria for a DSM anxiety disorder, 17% met the criteria for more than one anxiety disorder, and 57% also met criteria for clinically significant distinct anxiety. Results also indicated that 64% of the portion of the ASD sample that met the criteria for clinically significant distinct anxiety also met the criteria for a DSM anxiety disorder (Kerns et al., 2020). When examining the impact of intellectual functioning, Kerns et al. (2020) stated that the “present results suggest a nuanced relationship between a child’s developmental level and the quality, but not the quantity of anxiety symptoms in children with ASD” (p. 13). They found that the rates of clinically significant DSM anxiety disorder symptoms and clinically significant distinct anxiety symptoms were not significantly different when comparing intellectual functioning. However, children with intellectual impairment only met the criteria for specific phobia (42%), separation anxiety disorder (6%), and OCD (3%). Comparatively, the full range of DSM anxiety disorders was present in the portion of the ASD group that did not have intellectual impairment. These

results support the findings indicating that IQ plays a role in the type of anxiety experienced in children and adolescents with ASD (Kerns et al., 2020). Due to some of the variability in the results, this topic still warrants further research.

ASD Symptom Severity

The next factor explored is the relationship between the severity of ASD symptoms and the level of anxiety symptoms in children and adolescents with ASD. The research on this factor varies significantly, with some studies showing no correlation (Renno & Wood, 2013; Sukhodolsky et al., 2008) and other research findings support a linear relationship between ASD symptom severity and level of anxiety in this population (Gadow et al., 2005; Kanne et al., 2009; Muris et al., 1998). More current research on this topic suggests a positive correlation between these variables. However, the nature of this correlation may not be fully understood (Conner et al., 2020; Kerns et al., 2014). Studies that do support a linear relationship between ASD symptom severity and anxiety levels have found that more severe ASD symptoms are associated with lower levels of anxiety (Gadow et al., 2005; Muris et al., 1998). Other studies have found a correlation between increased levels of restricted and repetitive behaviors and higher anxiety levels in children and adolescents with ASD (Baribeau et al., 2020; Dellapiazza et al., 2022). The studies by Baribeau et al. (2020) and Dellapiazza et al. (2022) utilized a longitudinal research design, allowing them to analyze data from their samples at different points across time and draw conclusions based on the changes over time. From these longitudinal studies, they concluded that restricted and repetitive behaviors severity was a risk factor for increased anxiety symptoms and encouraged early screening and interventions for this population (Baribeau et al., 2020; Dellapiazza et al., 2022). Furthermore, these longitudinal studies found linear, unidirectional correlations between the severity of ASD symptoms and the level of anxiety experienced in

children and adolescents with ASD (Baribeau et al., 2020; Dellapiazza et al., 2022). These unidirectional findings indicate that the severity of the ASD symptoms is causing, or is responsible for, the corresponding anxiety levels.

Conversely to the unidirectional theories, this theory suggests that ASD symptoms can produce stressful situations that can create anxiety symptoms. Consequently, these resulting anxiety symptoms can begin to negatively impact the individual, which can potentially increase the severity of their ASD symptoms (Wood & Gadow, 2010). Based on this model, Wood and Gadow suggested that targeting anxiety symptoms in treatment could help children and adolescents with ASD reduce the severity of their ASD symptoms, which could help improve their overall level of functioning.

Some of the studies that have examined ASD symptom severity have also examined the role of emotion regulation and how it influences ASD symptom severity and level of anxiety (Conner et al., 2020; Samson et al., 2014). Conner et al. (2020) examined the relationship between emotion regulation abilities and the levels of anxiety in children and adolescents with ASD. Results from this study indicated that the level of emotion regulation impairment significantly predicated the level of anxiety symptom severity in children and adolescents with ASD. Samson et al. (2014) examined the relationship between emotion regulation and the core symptoms of ASD. In this study, they found that when compared to typically developing children in the control groups, children and adolescents with ASD were more likely to experience emotion dysregulation and had more severe symptoms of emotional dysregulation based on results from the Child Behavior Checklist (Samson et al., 2014). Results from this study also showed there was a correlation between emotion regulation impairment and all of the core symptoms of ASD. When examining these ASD symptoms, Samson et al. (2014) found that the

strongest predictor of emotion regulation impairment was the presence of repetitive behaviors. Additionally, the results also showed that there was a positive correlation between ASD symptom severity and level of emotion regulation impairment (Samson et al., 2014).

Both of these studies indicated that children and adolescents with ASD have been shown to be less likely to utilize effective adaptive behaviors and more likely to utilize maladaptive emotion regulation strategies (Conner et al., 2020; Samson et al., 2014). Together, these studies suggest that there is a correlation between emotion regulation and the severity of anxiety and ASD symptoms in children and adolescents with ASD (Conner et al., 2020; Samson et al., 2014). More specifically, these studies suggest impaired emotion regulation abilities may be responsible for increased anxiety symptoms in this population and ASD symptom severity may dictate the degree to which emotion regulation is impaired, especially repetitive behaviors (Conner et al., 2020; Samson et al., 2014). The findings from these studies provide evidence that emotion regulation needs to be the focus of treatment for children and adolescents with ASD (Conner et al., 2020; Samson et al., 2014). Overall, the research and related theories pertaining to the correlation between the level of anxiety symptoms and ASD symptom severity is significantly varied and still warrants further investigation.

Communication

Communication is another factor consistently mentioned in the research for its correlation with anxiety in children and adolescents with ASD. While social communication deficits are part of the diagnostic criteria for ASD, other aspects of communication are significantly correlated with ASD and impact how anxiety manifests in this population (American Psychological Association, 2013a). One of the aspects of communication that has significant co-occurrence rates with ASD is language disorders (Levy et al., 2010). This co-occurrence between ASD and

language disorders is so prevalent (approximately 63%) that the *DSM-5* requires practitioners to specify if the individual does or does not have an accompanying language impairment when making an ASD diagnosis (American Psychological Association, 2013a). Within the percentage of the ASD population that has a co-occurring language disorder, it is estimated that 25% to 30% of individuals with ASD are either minimally verbal or nonverbal (Levy et al., 2010; Rose et al., 2016). Additionally, research has also identified that roughly half of the individuals with ASD have notable deficits in semantics, grammar, and phonology (Levy et al., 2010). Furthermore, parents have consistently noted concerns about language development as the first concern about a child who is later diagnosed with ASD (Herlihy et al., 2015).

When examining communication, it is important to remember that it is a broad concept made up of smaller components (Reindal et al., 2021). Essential components of communication include the “form,” “content,” and “use” of the language. The form refers to concepts such as phonology, morphology, and syntax and the content refers to the concept of semantics (Reindal et al., 2021). The form and the content aspects represent a larger component called “structural language skills” while the “use” aspect also represents a larger component known as “pragmatic language skills” (Reindal et al., 2021). Pragmatic language skills refer to how the language is used in social or situation contexts (Reindal et al., 2021). Language disorders are assigned when there are deficits in one or more of these areas (Reindal et al., 2021). Research on these language skills suggests that both structural and pragmatic impairments are common in ASD, but pragmatic language disorders are more profound in this population (Reindal et al., 2021). However, research also suggests that structural language disorders were associated with lower competence in pragmatic language skills (Reindal et al., 2021). In a longitudinal study that investigated the relationship between communication and anxiety levels in children and

adolescents with ASD, Rodas et al. (2017) found that structural language skills were positively correlated with anxiety symptoms. This means that children with higher structural language skills experienced higher levels of anxiety symptoms and children with lower structural language skills experienced lower levels of anxiety. In response to this finding, Rodas et al. (2017) theorized that autistic children with higher structural language skills are more capable of understanding negative social information, which can lead to increased anxiety symptoms. In regard to pragmatic language skills, Rodas et al. (2017) found that higher pragmatic language skills were associated with lower anxiety levels and lower pragmatic language skills were associated with higher anxiety levels. They also found that cognitive ability levels were positively correlated with structural language skills but were not correlated with pragmatic language skills (Rodas et al., 2017). Overall, the findings from Rodas et al. (2017) suggest that children who have large gaps between their structural and pragmatic language skills are at greater risk of experiencing high levels of anxiety. In light of these findings, structural and pragmatic language skills should be assessed in this population as the findings could identify the individuals who are at a higher risk for developing anxiety.

Another area to consider when discussing communication is the portion of the ASD population that is either minimally verbal or nonverbal, which accounts for approximately 25% to 30% of the ASD population (Levy et al., 2010; Rose et al., 2016). Due to communication limitations, assessing internal states such as anxiety is difficult in this population (Tarver et al., 2021). Many of the measures used to assess anxiety are not normed for this population and rely on parents or caregivers to provide their interpretations of what they believe is going on internally for the child or adolescent (Tarver et al., 2021). While often the only option, this process is highly subjective and is believed to have significant impact on the accuracy of the

results (Tarver et al., 2021). In an effort to better understand parent recognition and management of anxiety in minimally verbal and nonverbal children and adolescents with ASD, Tarver et al. (2021) conducted a qualitative study utilizing semi-structured interviews rather than assessment measures. In this study, Tarver et al. (2021) examined the information collected in the interviews and established themes that were common among the parents of minimally verbal/nonverbal children and adolescents with ASD. When discussing the challenges associated with recognizing anxiety in this population, the parents consistently noted that reduced communication abilities and the overlap in symptomatology between ASD and anxiety disorders makes it difficult for them to distinguish between inherent ASD characteristics and symptoms of distress that are associated with anxiety (Tarver et al., 2021). Parents in this study also reported that anyone working with their child or adolescent needed to know the child very well to understand warning signs and triggers. Additionally, the parents expressed that many facilities that work with minimally verbal or nonverbal youth with ASD frequently experience high turnover rates, which can make it difficult to establish rapport and continuity in treatment (Tarver et al., 2021).

Furthermore, parents also indicated that managing anxiety in this population was very challenging and had significant impact on the quality of life for the child, the parent, and the family. Finally, the parents in this study expressed the need for more targeted interventions for this population that were empirically based as well as assessment measures that were normed for this population (Tarver et al., 2021). While the sample in this qualitative study was relatively small ($n = 17$), the themes that existed across these parents highlight the impact that communication limitations have on the children and their families.

Other research in this area has examined the directional or causal relationship between communication abilities and anxiety symptoms in children and adolescents with ASD. In other

words, other research examined whether anxiety symptoms cause or contribute to communication impairments, or whether communication impairments cause or contribute to anxiety symptoms, or if both variables impact each other in a bidirectional manner. Duvekot et al. (2018) examined the nature of the relationship between anxiety and communication in this population to determine if the effects of these variables were bidirectional. To examine this relationship, Duvekot et al. (2018) utilized 130 participants from the *Social Spectrum Study*, a larger study that incorporated participants from several treatment facilities in the Netherlands. These participants ranged in ages between 2.5 and 10 years old with average age of 6.7 years old, and 106 of the participants were male (Duvekot et al., 2018). Of the 130 participants who were initially assessed, 79 participated in the follow-up assessment that was approximately 24 months later on average (Duvekot et al., 2018). A crossed-lagged model was applied to the data collected and the longitudinal design of this study allowed for conclusions to be made about the directional nature of the relationship between communication and anxiety in this population. The results from this study indicated that anxiety symptoms were associated with greater social communication impairments across time; however, social communication impairments were not associated with greater anxiety levels across time (Duvekot et al., 2018). These results suggest that a unidirectional relationship exists between anxiety symptoms and the level of social communication impairment instead of a bidirectional relationship that is assumed in much of the previous research (Duvekot et al., 2018). In response to these findings, Duvekot et al. (2018) proposed that there may be multiple reasons for this unidirectional relationship and provided theories to support these reasons. The first theory was that the presence of anxiety symptoms could lead children and adolescents with ASD to avoid social situations, which could then decrease the opportunities to learn and practice all of the necessary social skills (Duvekot et al.,

2018). The second theory was that anxiety symptoms may increase the probability that this population is negatively judged by their peers which may lead to rejection or bullying. This can amplify their social difficulties and intensify negative feelings about themselves and their social communication abilities (Duvekot et al., 2018). The last theory that was proposed suggests that anxiety symptoms in this population create additional stress for parents, which may lead to these parents engaging in actions in an effort to protect the child. These actions can actually strengthen avoidance behaviors, which continue to limit the social opportunities and can negatively impact social communication abilities (Duvekot et al., 2018). While these theories still require further research, this study highlights the importance of early assessment and intervention of anxiety symptoms in this population. Early interventions could help reduce the negative impact that anxiety symptoms have on social communication abilities (Duvekot et al., 2018).

Sensory Reactivity

Another factor associated with influencing the manifestation of anxiety symptoms in children and adolescents with ASD is the differences in sensory reactivity (Khaledi et al., 2022; MacLennan et al., 2020, 2021). While hyperreactivity and hyporeactivity to sensory input is part of the diagnostic criteria for ASD, the sensory profiles can be extremely diverse, which has been shown to have a significant impact on the anxiety symptoms and the overall presentation of the children and adolescents in this population (American Psychiatric Association, 2013a; Khaledi et al., 2022; MacLennan et al., 2020, 2021). Research has shown that prevalence rates of atypical sensory reactivity in children and adolescents with ASD is extremely high. Marco et al. (2011) found that 96% of children who have been diagnosed with ASD experience atypical responses to sensory stimuli. In a more recent study, Balasco et al. (2020) found that approximately 90% of individuals with ASD have atypical responses to sensory information as well.

When examining the relationship between sensory abnormalities and anxiety symptoms in children and adolescents with ASD, research has shown that there is a definitive correlation between sensory abnormalities and anxiety symptoms (Khaledi et al., 2022; MacLennan et al., 2020, 2021). For example, Khaledi et al. (2022) examined the relationship between sensory difficulties and levels of anxiety in children with ASD. Results from this study indicated that higher levels of anxiety were associated with more sensory difficulties in this population. Furthermore, this study also found that higher levels of sensory impairments were also associated with greater communication deficits (Khaledi et al., 2022). These findings suggest that there may be a correlation among anxiety, communication, and sensory profiles; however, this is a recently published article and further exploration is needed to determine the exact relationship between these variables (Khaledi et al., 2022).

While acknowledging the association between sensory abnormalities and anxiety symptoms in children and adolescents with ASD, MacLennan et al. (2020) further examined the types of sensory reactivity and tried to determine their relationship to anxiety symptoms. To examine this correlation between sensory subtypes (i.e., sensory hyperreactivity, sensory hyporeactivity, and sensory seeking) and anxiety symptoms, this study utilized a sample of 41 children and adolescents with ASD who were between the ages of 3–14 years old (MacLennan et al., 2020). Results from this study suggest that sensory hyperreactivity was associated with higher levels of total anxiety with particularly high levels in separation anxiety and phobia/physical injury fears. Sensory hyporeactivity was associated with lower levels of total anxiety and results did not show any association between anxiety and sensory seeking (MacLennan et al., 2020). These findings about the sensory-seeking behaviors are in contrast to previous theories that suggest sensory seeking is used as a regulatory behavior when emotionally

aroused or used in times of hyporeactivity to provide as a source of stimulation (Lidstone et al., 2014; MacLennan et al., 2020). While MacLennan et al. (2020) did not find a statistically significant correlation between sensory seeking and anxiety, it was noted that the correlation between these variables was close to the significance thresholds for specific phobias and social anxiety. Since these variables were so close to meeting the significance thresholds, MacLennan et al. (2020) suggested that the relationship between these variables needed further investigation. In response to their findings, MacLennan et al. (2020) stated “Understanding how sensory reactivity differences relate to anxiety subtypes in autistic children has important implications for preventing the development of anxiety and for targeted anxiety interventions” (p. 792). They also recommended that future research should focus on developing objective anxiety assessments specific to individuals with ASD (MacLennan et al., 2020).

Additional studies have also found a correlation between sensory hyperreactivity and level of anxiety in children with ASD. MacLennan et al. (2021) examined the relationship among sensory reactivity, intolerance of uncertainty, and anxiety symptoms in 54 children with ASD who were between the ages of 3 to 5 (MacLennan et al., 2021). According to MacLennan et al. (2021), intolerance of uncertainty is defined as “difficulty with situations or contexts that are unforeseen or unpredictable” and is “considered to be a key cognitive component in the development and maintenance of anxiety through negatively appraising ambiguous or uncertain events” (p. 2306). While intolerance of uncertainty has been labeled as its own construct, it has similarities to ASD diagnostic criteria such as difficulty with change (MacLennan et al., 2021). In this study, MacLennan et al. (2021) examined the role of intolerance of uncertainty in relation to sensory reactivity and anxiety subtypes, if any. Results from this study suggested that sensory hyperreactivity, intolerance of uncertainty, and anxiety levels were intercorrelated (MacLennan

et al., 2021). More specifically, they found that the relationship between sensory hyperreactivity and anxiety is fully mediated by intolerance of uncertainty, and they also found that the relationship between sensory hyperreactivity and intolerance of uncertainty is fully mediated by anxiety (MacLennan et al., 2021).

Further analysis showed that sensory hyperreactivity was significantly related to total anxiety, particularly separation anxiety (MacLennan et al., 2021). Results also indicated that sensory hyperreactivity plays a key role in development of anxiety and intolerance of uncertainty may play an integral role in maintaining anxiety in children with ASD (MacLennan et al., 2021). In regard to the relationship between hyporeactivity and sensory seeking, they did not find significant correlations between these variables and anxiety or intolerance of uncertainty (MacLennan et al., 2021). It was suggested that the lack of correlation in these areas could potentially be due to the measures that were used, or it could be due to the fact that sensory hyporeactivity is more related to suppressed arousal and therefore may be more common in individuals with comorbid depressive disorders rather than anxiety disorders (MacLennan et al., 2021).

Because research has consistently demonstrated that sensory hyperreactivity or sensory over-responsivity is correlated with anxiety in children and adolescents with ASD, Green et al. (2012) further examined the directional relationship between these variables. Green et al. (2012) conducted a longitudinal study that utilized a sample of 149 toddlers (118 males, 31 females) who met criteria for ASD and their mothers. These toddlers were first assessed between the ages of 18–33 months old and then again between 30–45 months old, and data were compared using cross-lag analysis (Green et al., 2012). Results indicated that sensory over-responsivity was positively correlated with anxiety over time; however, anxiety was not correlated with sensory

over-responsivity across time (Green et al., 2012). These results suggest that the relationship between sensory over-responsivity and anxiety is unidirectional. Green et al. (2012) also explained that this unidirectional relationship supports the idea that sensory over-responsivity develops prior to anxiety and that the presence of sensory over-responsivity may be a risk factor for developing anxiety in children with ASD. These results are important because they could help parents or caregivers have more concrete indicators of anxiety to look for and this could help with earlier recognition and intervention (Green et al., 2012).

Other Comorbid Disorders

Comorbid disorders are extremely prevalent in children and adolescents with ASD and are another factor that can affect the manifestation of anxiety in this population. In a prominent and frequently referenced study, Simonoff et al. (2008) utilized a population-derived sample of 112 children and adolescents with ASD (ages 10–14 years old) to identify the prevalence rates of comorbid disorders and further explore risk factors associated with this population. This study found that 70% of children and adolescents with ASD had at least one comorbid disorder, and 41% of their sample met criteria for two or more comorbid disorders (Simonoff et al., 2008). Furthermore, results showed that social anxiety was the most common disorder in their sample with 29.2% of the participants meeting diagnostic criteria. ADHD was the second most prevalent diagnosis with 28.2% of the sample, and ODD was the third most prevalent diagnosis with 28.1% of the sample meeting diagnostic criteria (Simonoff et al., 2008). In another study that examined comorbid disorders in children and adolescents with ASD, Gjevik et al. (2010) found that 72% of their sample met criteria for at least one comorbid disorder. This study found that 41% of their sample met criteria for an anxiety disorder and 31% met criteria for ADHD (Gjevik et al., 2010). In a more recent meta-analysis, Lai et al. (2019) examined 96 articles pertaining to

co-occurring mental health diagnoses in individuals with ASD. Prevalence rates from this meta-analysis indicated that 28% of individuals with ASD also met diagnostic criteria for ADHD; 20% met diagnostic criteria for anxiety disorders; 13% for sleep-wake disorders; 11% for depressive disorders; 9% for OCD; 5% for bi-polar disorder; and 4% for schizophrenia (Lai et al., 2019). These studies show that other comorbid disorders, aside from anxiety disorders, are also highly prevalent in this population. The presence of additional comorbid disorders alters the diagnostic presentation, which can also alter the way anxiety manifests in this population.

Research has shown that ADHD is one of the most prevalent comorbid disorders in children and adolescents with ASD (Gjevik et al., 2010; Lai et al., 2019; Simonoff et al., 2008). While the available research has shown that these two disorders commonly co-occur, there is significant variance in the comorbidity rates across studies, ranging from 37% to 85% (Stevens et al., 2016). Stevens et al. (2016) noted this disparity in the comorbidity rates and intended to investigate further the relationship between these two disorders and attempt to identify more accurate comorbidity rates. Stevens et al. (2016) believed that the variation in the comorbidity rates was likely due to the shared core symptoms and the overlapping neuropsychological deficits present in ASD and ADHD. Another potential reason for the variation in comorbidity rates is that prior to the *DSM-5* release, the diagnosis of ADHD was not assigned if the individual also had an ASD diagnosis (Stevens et al., 2016). Due to this, much of the research on ASD and ADHD comorbidity prior to the release of the *DSM-5* was conducted in small clinics utilizing small samples, which might have had a significant impact on the results and limits generalizability (Stevens et al., 2016). Stevens et al. (2016) found that 42% of their sample met criteria for ASD and ADHD, and 17% of their sample met criteria for ASD, ADHD, and

intellectual disability, which brings the total sample to 59% who are diagnosed with ASD and ADHD.

When examining the relationship between comorbid anxiety and ADHD in children and adolescents with ASD, the literature is more limited. Among the available research, Avni et al. (2018) examined these variables in different variations and compared the results to standardized non-clinical samples to gain a better understanding of the relationship between these comorbid disorders. This study utilized a sample of 260 children and adolescents with ASD (228 males, 32 females) with an average age of 7.5 years old (Avni et al., 2018). All of the participants were administered full neurological, behavioral, and cognitive evaluations to get a complete picture of their diagnostic presentation (Avni et al., 2018). Following the evaluation, the participants were placed into one of four groups based on the results. These four groups were ASD alone, ASD and ADHD, ASD and anxiety, and ASD, ADHD, and anxiety (Avni et al., 2018). Results from this study indicated that 62.7% of the sample of children and adolescents with ASD also had clinically elevated symptoms of ADHD (Avni et al., 2018). Of the 62.7% of the sample who had comorbid ASD and ADHD, 67% had clinically elevated inattention symptoms and 57% had clinically elevated hyperactivity/impulsivity symptoms (Avni et al., 2018). Regarding anxiety symptoms, 44% of the children and adolescents with ASD in this study met criteria for clinically elevated anxiety symptoms. When comparing groups, results indicated that 53% of the ASD and ADHD group experienced clinically elevated symptoms of anxiety while 29.8% of the ASD without ADHD group experienced clinically elevated symptoms of anxiety (Avni et al., 2018). These results show that children and adolescents with ASD and ADHD are almost twice as likely to experience clinically elevated levels of anxiety. In addition to these comorbidity rates, Avni et al. (2018) also found that the ASD alone group had less severe ASD symptoms when compared

to the other three groups. The ASD and ADHD group showed more significant impairments in adaptive skills related to socialization and the group with ASD, ADHD, and anxiety was correlated with more impaired daily living skills (Avni et al., 2018).

Craig et al. (2015) also examined the relationship between ASD, ADHD, and anxiety and utilized a research design similar to Avni et al. (2018). For this study, Craig et al. (2015) utilized a sample of 181 children and adolescents who were divided into 4 groups: an ADHD group, an ASD group, an ASD and ADHD group, and a control group (Craig et al., 2015). Each of the participants was administered a comprehensive psychological assessment that included IQ measures, emotional and behavioral measures, ADHD measures, ASD measures, and adaptive skills measures (Craig et al., 2015). Data analysis revealed that the ASD and ADHD group had significantly higher scores than the other groups in multiple areas, including anxiety (Craig et al., 2015). From this study, Craig et al. (2015) indicated that the inattention and hyperactivity symptoms associated with ADHD, paired with the adaptive skills impairments associated with ASD, creates a challenging collection of symptoms for the individual that can contribute to their level of anxiety.

In addition to psychiatric comorbidities, research has shown that many children and adolescents with ASD have high levels of comorbid medical diagnoses that also impact anxiety levels in this population (Al-Beltagi, 2021; Fulceri et al., 2016; Mazurek et al., 2013; Tye et al., 2019). One of the medical disorders found to have high comorbidity rates with ASD is sleep disorders (Al-Beltagi, 2021; Tye et al., 2019). A review of medical comorbidities in ASD by Al-Beltagi (2021) found that approximately 80% of individuals with ASD experience sleep disorders, particularly insomnia. Research has also shown a bidirectional relationship between sleep and anxiety in children and adolescents with ASD (Al-Beltagi, 2021; Tye et al., 2019).

Prolonged sleep difficulties in this population can lead to many negative outcomes, including increased anxiety symptoms. These increased anxiety symptoms can create more anxiety around sleep, further exacerbating sleep difficulties (Al-Beltagi, 2021; Tye et al., 2019). This cycle can cause insomnia, which can significantly increase anxiety levels in this population (Al-Beltagi, 2021; Tye et al., 2019).

Another medical disorder that shares high comorbidity rates with ASD and has been shown to impact the levels of anxiety in this population is gastrointestinal (GI) problems. In a review about medical comorbidities in ASD, Al-Beltagi (2021) reported that that GI problems are present in 46% to 84% of individuals with ASD. The most common GI problem is chronic constipation, with an estimated comorbidity rate of 22% (Tye et al., 2019). Without treatment, these GI problems can create pain and discomfort for individuals and can lead to negative consequences, which includes increased anxiety symptoms (Tye et al., 2019). In comparison group studies, children with GI problems have been shown to have significantly higher anxiety symptoms than neurotypical control groups and higher anxiety symptoms than children with ASD without GI problems (Fulceri et al., 2016). Finally, research has also shown that children and adolescents with ASD and GI problems also had higher levels of anxiety symptoms and higher levels of sensory over-responsivity (Mazurek et al., 2013). This research suggests that GI problems, anxiety, and sensory over-responsivity symptoms in this population may be correlated and might have shared underlying mechanisms (Mazurek et al., 2013). The research about the impact of medical comorbidities on the anxiety levels in children and adolescent with ASD is still very limited and requires more investigate due to the significant number of individuals in this population who experience medical comorbidities (Al-Beltagi, 2021; Tye et al., 2019).

Manifestation of Anxiety in Children and Adolescents with ASD

The degree of heterogeneity that exists among children and adolescents with ASD has made it difficult to accurately describe how anxiety manifests in this population and how these symptoms of anxiety are conceptualized within the diagnosis of ASD (Kerns, Renno, Storch, et al., 2017; Postorino et al., 2017). While the previous sections of this chapter have highlighted some of the risk factors for this population, other challenges have been identified when trying to describe accurately how anxiety manifests in this population. When discussing these challenges, Postorino et al. (2017) stated:

The range of manifestations of anxiety that have been documented in ASD is large and heterogeneous, encompassing both classic and unconventional presentations, such as fears of change or novelty, worries surrounding circumscribed or specialized interests, and unusual phobias. The variability of such manifestations as well as the overlap of many anxiety and autism symptoms poses considerable challenges to the ascertainment and classification of anxiety symptoms in ASD. (p. 3)

In this statement, Postorino et al. (2017) mentioned one of the more recent challenges, the classic (traditional) and unconventional (atypical) presentations of ASD. This is an area of research that has garnered significant attention in recently and is an area that requires further examination (Kerns & Kendall, 2012; Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017; Postorino et al., 2017; Wood & Gadow, 2010).

Traditional and Atypical Symptoms

In ASD research, it has been consistently recognized that some children and adolescents with ASD present with anxiety symptoms that align with traditionally defined *DSM* anxiety disorders; however, a portion of this population present with anxiety symptoms that are more

atypical and seem to be more distinct to ASD (Kerns & Kendall, 2012; Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017; Postorino et al., 2017; Wood & Gadow, 2010). Kerns et al. (2014) designed a study that allowed them to further investigate the concepts of traditional and atypical presentations of anxiety in children and adolescents with ASD. For this study, they utilized a sample of 59 youth with ASD and their parents. The youth in this sample were between the ages of 7–17 years old with a mean age of 10.48 years old. Regarding other characteristics of this sample, 78% of the sample was male and 93% of the sample was Caucasian. To meet inclusion criteria, each participant was administered the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Scale to verify that they met criteria for ASD. Additionally, each participant was administered the Differential Ability Scales (DAS-II) or the Wechsler Intelligence Scale for Children (WISC-IV) to ensure that their full-scale IQ score was at least 60 or greater. Finally, the Clinical Evaluation of Language Fundamentals-Fourth Edition (CELF-4) was given to make sure that each of the participants were proficient enough in English to be included in the sample. After the sample was finalized, each of the participants and their parents were administered a series of questionnaires and semi-structured interviews (Kerns et al., 2014). Results from this study indicated that 63% of the sample met criteria for impairing anxiety symptoms, 17% met the criteria for traditional anxiety disorder, 15% met the criteria for impairing atypical anxiety symptoms, and 31% met the criteria for both. Regarding the portion of the sample that met the criteria for traditional anxiety disorders, the percentages were: specific phobias (30%), generalized anxiety disorder (22%), social anxiety (17%), separation anxiety disorder (10%), and OCD (2%) (Kerns et al., 2014). Results also revealed that 50% of the sample that met the criteria for one traditionally defined anxiety disorder also met the criteria for more than one. Regarding atypical anxiety, Kerns et al. (2014) divided these symptoms into four

categories. The first category was “anxiety around routine, novelty, and restricted interest” and this was defined as “In the absence of generalized worry: Anticipatory worry or fear related to minor changes in routine (e.g., new or aberrant traveling routes); changes in daily schedule; excessive worry about losing access to special interest or about rule-breaking” (Kerns et al., 2014, p. 2861). The second category was “unusual specific fears,” and this category was defined as “In the absence of a generalized sensitivity to noise or sensory stimuli: Fears of baby crying; coughing; radio jingle; spider webs; happy birthday song; supermarkets; bubbles; balloons; thorns; fire” (Kerns et al., 2014, p. 2861). The third atypical anxiety category was “social fearfulness,” and this was defined as “In youth who lack an awareness of social judgment: somatic symptoms in social settings; frantic efforts to escape and avoid settings where other persons are present; increased self-injurious and aggressive behavior in social settings” (Kerns et al., 2014, p. 2861). The last atypical anxiety category was the “compulsive/ritualistic behavior,” and it was defined as “In the absence of clear desire to prevent distress or a feared outcome: Mealtime rituals, verbal rituals, insistence on use of specific phrases, insistence that computers be turned off, doors closed, sleeves rolled down, shoes kept on in car” (Kerns et al., 2014, p. 2861). Results indicated 22% of the sample met the criteria for the interfering worry and fear around routines, novelty, and restricted interests category, 12% met the criteria for the unusual fears category, 8.5% met the criteria for social fear without concern for social rejection category, and 8.5% met the criteria for the compulsive/ritualistic behaviors category (Kerns et al., 2014). Overall, Kerns et al. (2014) reported that the results indicated there were “two qualitatively and phenomenologically distinct mechanisms of anxiety in ASD” (p. 2853). When describing these two types of anxiety that are present in children and adolescents with ASD, Kerns et al. (2014) stated “one akin to anxiety as it occurs in youth without ASD (e.g., traditional anxiety) and one

wherein anxiety is altered in its pathogenesis and presentation by its interaction with ASD-related traits (e.g., atypical anxiety)” (p. 2853). Traditional anxiety was described as a true comorbidity and resembles the presentation of anxiety in individuals without ASD. Furthermore, atypical anxiety was described as a distinct manifestation of anxiety that is not captured by *DSM* criteria but is still impairing to the youth with ASD who experience these symptoms. When theorizing about the atypical anxiety symptoms, Kerns et al. (2014) suggested this type of anxiety may not be unique to ASD and argued that these types of anxiety symptoms are also experienced in other diagnostic groups to varying degrees. It was also theorized that these symptoms may be captured by the unspecified anxiety disorder diagnosis, but Kerns et al. (2014) mentioned that further research is needed to investigate this theory. Further statistical analysis was also conducted to evaluate if there were any variables that served as predictors for typical and atypical anxiety symptoms in this sample (Kerns et al., 2014). The variables that were examined were IQ, language ability, hypersensitivity, anxious cognitive style, and ASD symptoms. Results indicated that predictors for traditional anxiety symptoms were language ability, hypersensitivity, and anxious cognitive style. Predictors for atypical anxiety symptoms were anxious cognitive style and ASD symptoms. These factors are important in furthering the current understanding of risk factors associated with this population, particularly when examining traditional and atypical anxiety symptoms.

Due to increasing evidence of traditional and atypical anxiety manifestations in children and adolescents with ASD, Kerns, Renno, Storch, et al. (2017) created a list that included the differences in triggers and how anxiety is manifested in traditional versus atypical or ASD-related anxiety. For the precipitants or triggers section, the traditional anxiety triggers included specific fears common in children without ASD, including fears such as animals, doctors,

insects, and germs. Other triggers were separation from caregivers, crowds, teasing, bullying, unwanted social attention, worrying about the thoughts/opinions of others, academic demands, and meeting deadlines. Atypical precipitants/triggers include specific, idiosyncratic fears that are not typically seen in individuals without ASD. Examples provided by Kerns, Renno, Storch, et al. (2017) were chocolate buttons, toilets, and men with beards. Other triggers were transitions, disruptions to routine, sensory over-stimulation, confusion about expectations in social situations, and being prevented from engaging in circumscribed behaviors or interests.

The second part of the list included the manifestations for both the traditional anxiety symptoms and the atypical or ASD-related anxiety symptoms. This list was broken down into physiological/somatic manifestations, cognitive manifestations, and behavioral manifestations. For the traditional anxiety manifestation, the physiological symptoms include, increased heart rate, sweating, tearful, overwhelmed, anxious facial expressions or body language, crying or screaming, sleep disturbances, eating disturbances, and shaking or restless. As for the physiological manifestation for the atypical symptoms, Kerns, Renno, Storch, et al. (2017) indicated that current research has not explored the way that physiological symptoms of anxiety manifest in children and adolescents with ASD. It was noted that this is an area needing further investigation to determine whether youth with ASD are experiencing physiological symptoms similar to those of youth without ASD (Kerns, Renno, Storch, et al., 2017). Research in this area could further the current understanding of how anxiety manifests and is conceptualized in children and adolescents with ASD. Regarding the manifestation of traditional cognitive symptoms of anxiety in this population, Kerns, Renno, Storch, et al. (2017) reported that these symptoms include cognitive distortions and perseveration on perceived threats or consequences. The final section of the list is the different types of behavioral manifestations of anxiety in this

population. The traditional behavioral symptoms of anxiety include attempting to escape/avoid /withdrawal, reassurance seeking, and distraction. The atypical behavioral symptoms include increase in repetitive/ritualistic behaviors or interests, increase in challenging behaviors or acting out, and an increase in sensory behavior (Kerns, Renno, Storch, et al., 2017). Kerns et al. (2020) also were examining the traditional versus atypical anxiety in youth with ASD and varied IQ. In this study, they found that IQ does play a role in the type of anxiety that is experienced by this population and stated “findings indicate that reliance on DSM-specified anxiety disorders alone may result in substantial underestimation and incomplete characterization of impairing anxiety problems in children with ASD” (Kerns et al., 2020, p. 12). Overall, understanding that anxiety manifests in traditional and atypical ways in this population can help further research efforts as well as help mental health providers recognize these symptoms, further the conceptualizations of these patients, and provide appropriate treatment that addresses these symptoms of anxiety.

Impact of COVID-19

Another factor that has impacted the manifestation of anxiety in children and adolescents with ASD is the COVID-19 pandemic. The first cases of COVID-19 were detected in China in 2019, and the virus quickly spread to other countries across the world (World Health Organization, 2023). On January 30, 2020, the World Health Organization declared COVID-19 a public health emergency of international concern (PHEIC) and, after continued global outbreak, declared it a global pandemic on March 11, 2020 (World Health Organization, 2023). Three years later, on May 5, 2020, the World Health Organization announced that COVID-19 no longer met the criteria for a PHEIC. The World Health Organization went on to explain that this does not mean the pandemic is over. However, it no longer met the requirements for a global emergency (World Health Organization, 2023). Upon the arrival of the pandemic, governments

across the world implemented measures that were focused on containing the virus, including curfews, school closures, quarantine periods, social distancing, and mask policies, to name a few (Milea-Milea et al., 2023). The measures taken during the pandemic have significantly disrupted the lives of children and adolescents with ASD and their families (Manning et al., 2021).

Due to the widespread impact of COVID-19, heavy emphasis has been placed on researching how the pandemic has affected different populations across the world (Milea-Milea et al., 2023; Pai et al., 2022). While this research is expected to continue to develop over time, currently, two systematic reviews have been published about the impact of the COVID-19 pandemic on children and adolescents with ASD (Milea-Milea et al., 2023; Pai et al., 2022). After evaluating articles for inclusion and exclusion criteria, the review by Milea-Milea et al. (2023) included 21 studies and the review by Pai et al. (2022) included 26 articles. Results from these reviews indicate that when compared to neurotypical children and adolescents, children and adolescents with ASD have been more significantly impacted in negative ways by the COVID-19 pandemic. Results also suggest that these findings also apply to the families of children and adolescents with ASD (Milea-Milea et al., 2023; Pai et al., 2022). Findings from these reviews are examined in further detail below.

Strict adherence to routines is one of the diagnostic criteria for ASD, so the COVID-19 pandemic was particularly challenging for children and adolescents with ASD because it significantly disrupted their daily routines. In an effort to reduce the spread of COVID-19, schools were shut down and mandatory stay-at-home orders were implemented in many areas. Not being able to attend school and being confined to their homes for extended periods of time, this negatively impacted children and adolescents with ASD and their families in a variety of ways. Vasa et al. (2021) found that when compared to their pre-pandemic presentation, 59% of

children and adolescents with ASD experienced either worsening psychiatric symptoms and/or new psychiatric symptoms during the COVID-19 pandemic. Results from multiple studies indicate that increases in anxiety symptoms constitute the most notable change in this population (Milea-Milea et al., 2023; Pai et al., 2022; Vasa et al., 2021). Concordant with these findings, it was also discovered that many children and adolescents with ASD experienced increased behavioral problems during the COVID-19 pandemic. Güller et al. (2021) found that 33.4% of parents of children and adolescents with ASD endorsed increased behavioral difficulties during the COVID-19 pandemic. More specifically, 50.4% of the parents reported that their child had an increase in their repetitive or stereotyped behaviors and 46.6% endorsed an increase in levels of hyperactivity (Güller et al., 2021).

Furthermore, Mutluer et al., (2020) examined the behavioral implications of the pandemic on children and adolescents with ASD and found that 55% of the parents of their sample indicated that their child had an increase in aggressive behavior during the pandemic. Results from this study also showed that 26% of the parents reported that their child's tic behaviors either got more severe or they developed new tics. This study also noted that 29% of the parents indicated that their child's communication skills had deteriorated since the beginning of the pandemic. In addition to these emotional and behavioral difficulties, Mutluer et al. (2020) also found that 44% of the parents indicated that their child or adolescent with ASD had experienced sleep difficulties since the start of the pandemic. Finally, change in appetite was also noted by 33% of their sample (Mutluer et al., 2020).

To further complicate the issues this population was experiencing during the COVID-19 pandemic, many of these youths were receiving various services through their school. Therefore, when the schools closed, many of these youths experienced disruption to these different services.

Students who received services in the community also experienced disruptions during the pandemic. In a study about the impact that school closures had on students with ASD during COVID-19, Genova et al. (2021) found that 78.63% of their sample experienced disruptions in their therapeutic services. The introduction of telehealth and virtual learning was able to provide access to educational and therapeutic services. However, many parents expressed that they believed virtual service delivery was less effective for children and adolescents with ASD (Genova et al., 2021; White et al., 2021). Concerning virtual learning, Genova et al. (2021) found that 48.53% of parents in their sample believed their child or adolescent was falling behind in school, and 57.35% expressed concern that their child was less prepared to return to school when schools reopened. Many parents of children with ASD expressed concern about reintegration into society, particularly returning to school (Bellomo et al., 2020). Uncertainties around COVID-19 protocols make it challenging for parents to help prepare their children, and the routines differ from the pre-pandemic routines that these children and adolescents used to (Bellomo et al., 2020). Finally, Genova et al. (2021) found that parents in this study also reported virtual social events were difficult for children with ASD and 54.33% of the parents in the sample thought their child or adolescent was being excluded from these types of events with peers.

While research shows that the COVID-19 pandemic had significant impact on children and adolescents with ASD, the research also indicates the parents/caregivers were significantly impacted as a result Alhuzimi (2021). In addition to trying to manage the increase in social, emotional, and behavioral challenges in their children with ASD, these parents also were trying to adjust to the stay-at-home orders (Milea-Milea et al., 2023). Many of these parents had to adjust to working remotely while trying to assist their children with virtual learning and

telehealth service (Milea-Milea et al., 2023). The lack of support during this time and the ineffectiveness of telehealth services led to an increase in stress for parents during this time. Milea-Milea et al. (2023) reported that parental stress levels increased 43% during the pandemic as parents struggled to handle all of the demands placed on them. Studies have also shown that all of these variables parents of youth with ASD experienced during the COVID-19 pandemic had a significant impact on their quality of life. Pecor et al. (2021) indicated that parents/caregivers of children with ASD had a lower quality of life during the COVID-19 pandemic when compared to the parents/caregivers of neurotypical children. This lower quality of life was also associated with greater levels of anxiety and depression (Pecor et al., 2021). Future research is expected to continue to examine the impact of the COVID-19 pandemic on children and adolescents with ASD and their families.

Limitations

Although the research that examines the role of anxiety in ASD has advanced significantly since the first observations that were made by Leo Kanner (1943) and Hans Asperger (Frith & Mira, 1992), the current research has identified several limitations that continue to make it challenging to fully explain the role of anxiety in children and adolescents with ASD. These limitations result from the large heterogeneity in this area of research (van Steensel et al., 2011). While heterogeneity can be caused by various factors, in this area of research, it is primarily due to methodological differences (van Steensel et al., 2011). The limitations outlined below have been consistently mentioned throughout the literature and are impacting the current understanding of how anxiety manifests and is conceptualized in this population. These limitations need to be addressed to continue to advance the research in this

area and further develop the understanding of anxiety manifestation and conceptualization in this population.

One of the main limitations consistently mentioned in this area of research is the lack of a gold-standard assessment that measures anxiety in ASD (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014; van Steensel et al., 2011; van Steensel et al., 2014; Vasa & Mazurek, 2015). The primary critique about the assessments used to evaluate aspects of anxiety in children and adolescents with ASD is that many of these measures have not been validated or specifically developed for this population. This critique also applies to the uncertainty around the reliability of these measures when used with children and adolescents with ASD. Since the reliability and validity of many of these measures that are being used in research studies have not been tested and verified in this population, the results from these studies need to be interpreted with caution (Lecavalier et al., 2014).

The second concern about these assessments is that they do not account for potential differences in anxiety symptom manifestation in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). When discussing this topic, Kerns, Renno, Storch, et al. (2017) made the following statement:

While there is general agreement that assessments need to distinguish the superficial similarities of core ASD symptoms where they overlap, e.g., social avoidance versus social anxiety, repetitive, stereotyped language versus reassurance seeking, there is presently no agreement whether anxiety symptom definitions and/or criteria should be modified in ASD. (p. 8)

Additionally, due to the overlap in symptomatology, researchers have questioned whether these assessments are accurately assessing the anxiety symptoms in this population or if they are

assessing ASD symptoms (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Furthermore, some of the anxiety symptoms commonly seen in this population are also ambiguous, such as fear of change, and researchers have also questioned whether these assessments are capturing these ambiguous, non-traditional anxiety symptoms (Kerns, Renno, Storch, et al., 2017). Evidence of this occurred in a study by White et al. (2012); they assessed the anxiety levels of adolescents with ASD and anxiety disorders seeking treatment for their anxiety symptoms. Results from this study revealed that just 23% of their sample reported clinically elevated anxiety scores using the Multidimensional Anxiety Scale for Children (MASC) (White et al., 2012). These results support the notion that these assessment measures that are not validated for individuals with ASD may not be capturing the essence of anxiety in this population.

The final concern about using assessment measures with children and adolescents with ASD is that a significant portion of this population struggles to accurately describe their symptoms of anxiety (Kerns, Renno, Storch, et al., 2017). These difficulties may be due to alexithymia, intellectual disability, nonverbal or minimally verbal, or other unique circumstances. Due to this significant percentage, researchers frequently need to rely on other informants, such as parents/guardians, caregivers, or teachers to fill out assessments rather than using self-reports. While these parent assessment measures are often the only option, they require parents to make inferences about the internal states of their child or adolescent based on external and contextual cues (Kerns, Renno, Storch, et al., 2017). Making these inferences can be difficult for parents and research has shown that these parent reports are often inaccurate (Kalvin et al., 2020; Kerns, Renno, Storch, et al., 2017). Research has shown that inconsistencies between self and parent reports are common and suggests that these inconsistencies are even

larger when assessing for internalizing symptoms. (Kalvin et al., 2020). In addition to these findings, research has also found that parents of children and adolescents in this population frequently overreport anxiety symptoms, especially when the child or adolescent has more severe ASD symptoms (Kalvin et al., 2020). This adds support to the claim that differentiating between core ASD symptoms and symptoms of anxiety can be difficult for informants and can impact the results of these assessments and consequently the research in this area of study (Kalvin et al., 2020; Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014).

Another limitation to consider is how diagnostic criteria are operationalized, defined, and applied in research studies. The primary function of the *DSM-5* and other diagnostic classification systems is to aid clinicians in assessing constellations of symptoms and assigning a diagnosis. While these diagnostic classification systems provide valuable information to aid clinicians, they do not provide guidance to researchers about how these symptoms should be operationalized, defined, and applied in studies (Kerns, Renno, Storch, et al., 2017).

Furthermore, there are no parameters for which assessment measures should be utilized in these studies. These are all decisions left to the discretion of the researchers. Due to this lack of set parameters, diagnostic criteria can be measured, operationalized, and applied in a variety of ways which makes it difficult to compare research (Kerns, Renno, Storch, et al., 2017; Vasa et al., 2017). When talking about this limitation, Kerns et al. (2014) stated “the way anxiety symptoms in ASD are measured and described varies substantially across studies, further limiting our ability to draw conclusions about the prevalence, presentation and correct diagnostic allocation of atypical symptoms” (p. 3). This is a methodological limitation that is pervasive across all psychiatric research and is responsible for a significant portion of the variability that exists across studies (Kerns, Renno, Storch, et al., 2017). More consistency across assessment measures

and more agreement about how to operationalize variables is needed to reduce the significant variability in this area of research.

Aspects related to sample ascertainment and control groups have also been identified as limitations in this area of research (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Rice et al., 2012). Regarding sample ascertainment, Kerns, Renno, Storch, et al. (2017) stated, “The most accurate prevalence estimates will be obtained from studies that use epidemiological methods to derive samples that either include the entire population of interest (target population) or are randomly selected from this population” (p. 9). While there are a variety of different ways in which samples are selected, Rice et al. (2012) also noted “Epidemiologic studies that systematically screen the population, which may result in the identification of individuals who were not previously classified as having an ASD, generally result in higher and more complete prevalence estimates” (p. 4). While research has indicated that epidemiological methods will provide the most accurate prevalence estimates in this population, these methods are very time-consuming, so they are difficult to achieve (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Rice et al., 2012). Due to this, many researchers turn to other methods to obtain their samples, including health registers, clinics or schools that specialize in working with individuals with ASD, or volunteer samples that are recruited for research studies (Kerns, Renno, Storch, et al., 2017). Obtaining samples in this manner, while sometimes the only solution, can lead to biased findings and makes it difficult to compare research and limits the generalizability of the findings (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009).

In addition to sample ascertainment, research has also identified limitations around control groups (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009). By definition, a control group is a separate comparison group used to help contextualize the finding of the research

(Kerns, Renno, Storch, et al., 2017). Identifying a control group in studies that involve ASD can be challenging for researchers due to the number of variables that need to be matched or controlled for in these studies (Kerns, Renno, Storch, et al., 2017). The methods used to select and structure the control groups are where the limitations occur (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009). In a critical literature review by MacNeil et al. (2009) they reviewed 13 studies that examined anxiety in ASD and critiqued the methods of these studies and discussed the limitations caused by these methods. Regarding the control groups, MacNeil et al. (2009) reported that only 7 of the 13 studies used non-ASD control groups, which limits comparisons to other populations. This review also stated that many of the control groups were not matched on demographic characteristics and functioning levels of the other comparison groups, which impacts the accuracy of the results (MacNeil et al., 2009). The methods used to compose control groups need to be closely examined when analyzing research findings and considering the results. Together, the factors of significant influence and the limitations discussed in this chapter have shaped the current understanding of how anxiety manifests and is conceptualized in children and adolescents with ASD. The factors of significant influence need to be accounted for in future research and the limitations need to be addressed to advance research in this area.

Chapter IV: HOW IS ANXIETY CONCEPTUALIZED, ASSESSED, AND TREATED IN ASD?

Since the first observations of anxiety symptoms that were noted by Leo Kanner and Hans Asperger in their first descriptions of ASD, the relationship between these two diagnoses has been heavily researched (Frith & Mira, 1992; Kanner, 1943; Volkmar & McPartland, 2014). Throughout time, the research on the role of anxiety in children and adolescents with ASD has advanced, which has changed the way this co-occurrence is defined, classified, assessed, treated, and conceptualized. Currently, the large heterogeneity that exists within this population and the limitations outlined in the previous chapter have made it difficult to further our conceptualization of the role of anxiety in youth with ASD. Being unable to advance the understanding of how anxiety is conceptualized in youth with ASD also limits the understanding of how to best assess and treat anxiety in this population (Kerns, Renno, Storch, et al., 2017; Wood & Gadow, 2010). Despite these challenges, the following chapter discusses the current conceptualization theories/models of the role of anxiety in ASD, the treatments that have been found to be effective with this population, and the assessments that have been found to be effective in accurately assessing anxiety in children and adolescents with ASD.

Models/Theories of the Role of Anxiety in ASD

Due to the limitations mentioned above, the literature on the conceptualization of the role of anxiety in youth with ASD is limited. Despite the limitations in this area, two studies have thoroughly investigated this relationship and have developed theories and models to support their conceptualization findings (Kerns & Kendall, 2012; Wood & Gadow, 2010). In the first article, Wood and Gadow (2010) sought to explore the nosology and the pathogenesis of anxiety disorders in children and adolescents with ASD. From this exploration, Wood and Gadow (2010)

also presented a model illustrating how they believe anxiety is conceptualized in this population in hopes of guiding future research. When examining the co-occurrence of these two disorders in youth with ASD, Wood and Gadow (2010) outlined four possible relationships between anxiety disorders and ASD. The first possibility was that anxiety and ASD represents a “‘true’ comorbidity, wherein the comorbid condition (anxiety in ASD) is phenotypically and etiologically identical to the monomorbid condition (anxiety) in a typically developing individual (i.e., someone with no ASD diagnosis)” (Wood & Gadow, 2010, p. 281). The second possible co-occurring relationship is a “true anxiety phenotypically altered by ASD pathogenic process, resulting in an ASD-specific variant that arguably could be considered a unique syndrome, but nevertheless is not a manifestation of the ASD diathesis” (Wood & Gadow, 2010, p. 281). The third possibility is “an aspect of the ASD diathesis, possibly with partially differing etiology from individuals with ASD who do not evidence anxiety (i.e., phenotypic heterogeneity or unique subtypes of ASD rather than true comorbidity)” (Wood & Gadow, 2010, p. 281). The last possibility is a “false or artifactual comorbidity, stemming from inaccurate differential or dual diagnosis” (Wood & Gadow, 2010, p. 281).

From their analysis, Wood and Gadow (2010) created a unidirectional model that outlined multiple avenues of how ASD-related stressors could contribute to or cause mood dysregulation and anxiety symptoms, which could then result in negative consequences. In one potential avenue, the ASD-related stressors of social confusion/unpredictability of social situations and/or peer rejection due to ASD symptoms can lead to either social anxiety symptoms or negative affectivity/other types of anxiety symptoms/depressive symptoms. If these ASD-related stressors led to social anxiety symptoms, then this could result in either an increase in social avoidance or it can result in an increase in ASD symptom severity, and/or development or

increase in behavioral problems, and/or increased distress that contributes to decreased quality of life. If these ASD-related stressors led to negative affectivity/other types of anxiety symptoms/depressive symptoms, then this could result in an increase in ASD symptom severity, and/or development or increase in behavioral problems, and/or increased distress contributing to decreased quality of life. In the second potential avenue, the ASD-related stressor is related to preventing individuals from engaging in preferred/repetitive behaviors or punishing them for doing so. This ASD-related stressor can lead to negative affectivity/other types of anxiety symptoms/depressive symptoms, resulting in ASD symptom severity, and/or development or increase in behavioral problems, and/or increased distress contributing to decreased quality of life. In the last potential avenue, the ASD-related stressor is related to sensory sensitivities and the frequency of these negative experiences. This ASD-related stressor can lead to negative affectivity/other types of anxiety symptoms/depressive symptoms, resulting in ASD symptom severity, and/or development or increase in behavioral problems, and/or increased distress contributing to decreased quality of life. When explaining this model, Wood and Gadow (2010) stated that anxiety in ASD may be “a downstream consequence of ASD symptoms (e.g., via stress generation through experiences like social rejection) (p. 287). This increase in social anxiety symptoms could explain social avoidance in many individuals with ASD, as opposed to low social motivation. Wood and Gadow (2010) explained that anxiety in ASD may also be “a mediator or moderator of ASD symptom severity” (p. 287). To clarify this point, as a mediator, this would mean that as anxiety increases, so does its negative impact on this individual. As a moderator, it is anticipated that youths who have ASD and anxiety have more difficulty than youths with just ASD. The third way anxiety in ASD was explained by Wood and Gadow (2010) was as a “proxy of core ASD symptoms (i.e., because of poor discriminant validity between

measures of anxiety and ASD)” (p. 287). In this study, Wood and Gadow (2010) stated that research on how anxiety is conceptualized in individuals with ASD is “deadlocked” (p. 284) until assessment measures can accurately assess for all of the types of anxiety symptoms present in this population. Last, Wood and Gadow (2010) made the following statement that sums up their proposed model:

we propose that many of the core symptoms of ASD can lead to stressful experiences that promote anxiety. Heightened anxiety has the potential to increase the severity of certain ASD symptoms, such as speech and language deficits, rigidity, and repetitive behavior, as well as to contribute to or account for social avoidance, behavioral problems (e.g., tantrums), and poor perceived quality of life. (p. 288)

With improved assessment measures that have been created and validated for this population, this model needs to be further examined to determine its accuracy. This model also suggests targeting co-occurring anxiety in treatment for individuals with ASD may also help to reduce ASD symptom severity and other ASD-related impairments (Wood & Gadow, 2010).

Kerns and Kendall (2012) also examined the role of anxiety in ASD. While this article did not include a theoretical model, Kerns and Kendall (2012) stated that their review “addresses the optimal conceptualization of the anxiety seen in ASD and asks if such symptoms are a part of ASD, a comorbid condition, or a novel presentation of anxiety altogether” (p. 323). While exploring the potential roles of anxiety in ASD, Kerns and Kendall (2012) set out to answer three questions they referred to as “distinctions” (p. 324). The first distinction was “Do anxiety symptoms in ASD represent an independent, co-occurring pathology or simply a manifestation of the ASD diathesis?” (Kerns & Kendall, 2012, p. 324). The second distinction that was “If independent (as determined by Distinction 1), do anxiety symptoms represent a ‘true

comorbidity' or a unique, ASD-related anxiety syndrome or variant?" (Kerns & Kendall, 2012, p. 324). The third distinction was "If comorbid or unique (as determined by distinction 2), does anxiety represent a sequela of ASD, a covariant (i.e., a correlated, but causally unrelated characteristic resulting from shared risk), or a mixture of the two?" (Kerns & Kendall, 2012, p. 324).

When evaluating the first distinction, Kerns and Kendall (2012) found evidence that supports the notion that anxiety and ASD are likely co-occurring disorders rather than part of the ASD diagnosis. One piece of supporting evidence for this finding was that while prevalence rates of anxiety disorders in individuals with ASD are high, no studies have found that 100% of their samples meet the diagnostic criteria for both disorders. Therefore, since anxiety is not universal in all individuals with ASD, anxiety is likely a co-occurring symptom rather than a core ASD symptom. Kerns and Kendall (2012) reported that the variation in the prevalence rates of anxiety in ASD is due to a variety of factors such as methodology, differences in how samples are identified and composed, differences in how anxiety is operationalized throughout the research, and lack of assessments that are validated for measuring anxiety in ASD samples. Studies that contain community and epidemiological samples of children and adolescents with ASD indicate that it is likely that the true prevalence rates of anxiety in ASD samples are between 39–50% (Kerns & Kendall, 2012). Additionally, Kerns and Kendall (2012) indicated that the research has found factors such as age, intellectual functioning, and ASD symptom severity have all been found to influence the type of anxiety symptoms that individuals with ASD experience and how the anxiety symptoms manifest in this population. This finding also suggests that anxiety is a co-occurring symptom with ASD.

Since the evidence from the first distinction supported the notion that anxiety co-occurred independently from ASD, the second distinction was examining whether anxiety in ASD is a true comorbidity or a syndrome that is unique to ASD (Kerns & Kendall, 2012). When exploring the second distinction, Kerns and Kendall (2012) examined multiple factors about anxiety in ASD including the prevalence of specific anxiety disorders, anxiety severity, presentation of anxiety in this population, onset and trajectory of anxiety, and response to treatment. When drawing conclusions about these factors, the findings about youth with ASD were compared to neurotypical youth without ASD. Prior to answering the second distinction, Kerns and Kendall (2012) noted that due to the differences in sampling, methodology, how anxiety is operationalized in studies, and lack of anxiety measures validated for use in the ASD population, impacted how the first distinction was answered. Consequently, they also noted that the second distinction should also be interpreted with caution due to the uncertainty around their response to the first distinction. Overall, Kerns and Kendall (2012) stated that they had mixed findings and indicated that there was evidence that supported the concept of anxiety as a comorbid disorder in ASD and there was also evidence that supported the concept that anxiety was a syndrome unique to ASD. More specifically, Kerns and Kendall (2012) explained that there are many similarities when comparing anxiety in youth with ASD to the anxiety in neurotypical children, which suggests that anxiety and ASD may operate as comorbid disorders. However, the differences in prevalence rates and unusual presentation of specific anxiety disorders in youth with ASD, particularly with social anxiety disorder, specific phobias, and OCD, suggest that anxiety in youth with ASD may be unique to this population. For specific phobias, findings suggested that youth with ASD experienced phobias that were similar to youth without ASD. However, a significant number of youth with ASD experienced specific phobias that were uncommon and

were not experienced by youth without ASD. In OCD, a significant portion of the youth with ASD experienced obsessions that were unique or differed from the common obsessions seen in youth without ASD. Additionally, youth with ASD have been found to have significantly lower rates of premonitory distress, which differs from youth with OCD who do not carry an ASD diagnosis (Kerns & Kendall, 2012). Finally, social anxiety in youth without ASD was found to have less of a focus on social evaluation, which also differed from youth without ASD. Kerns and Kendall (2012) expressed that advancements in assessment measures are needed to fully understand whether anxiety is a comorbid disorder or a unique syndrome in this population.

The third distinction was examining the etiology of anxiety in ASD and trying to determine whether the anxiety was a sequela of ASD, a covariant of ASD, or both (Kerns & Kendall, 2012). When investigating the research for this distinction, Kerns and Kendall (2012) concluded “the etiology of anxiety in ASD is unknown and difficult to study given ongoing confusion about the differentiation and relationship of these disorders” (Kerns & Kendall, 2012, p. 340). While the etiology remains unknown, Kerns and Kendall (2012) reported that some theorists have found some initial evidence but require more extensive research. One of these theories proposes that there is a direct causal relationship between ASD symptoms and anxiety disorders. This theory suggests that the deficits that are commonly associated with ASD may contribute to the development of anxiety disorders or may predispose an individual to experience symptoms of anxiety. Another theory is that sensory over-responsivity may be responsible for creating anxiety around certain stimuli, which can then develop into a phobia of that stimuli, typically loud sounds. Kerns and Kendall (2012) also suggested that youth with ASD and higher levels of self-awareness may recognize their social deficits, which could lead to increased social anxiety symptoms. Finally, Kerns and Kendall (2012) noted that both casual and covariation

models of anxiety in ASD are possible due to the heterogeneity of the presentations in this population as well as the high prevalence rates.

This review by Kerns and Kendall (2012) utilized a cascading format where each of the distinctions built upon the findings from the previous distinction. This format had a significant impact on this review because of the degree of uncertainty that surrounded the findings in the first distinction that is due to several limitations in the current research. Limitations such as methodological differences in the current research, differences in how diagnostic variables are operationalized, and lack of ASD-validated assessment measures continue to inhibit the ability to accurately define the role of anxiety in ASD. Kerns and Kendall (2012) expressed that a “coordinated methodology” is needed in the research to be able to understand the nature of the relationship between anxiety and ASD (p. 340). These current limitations make it difficult to formulate a conceptualization of the role of anxiety in this population.

Treatment of Anxiety in ASD

When attempting to understand and conceptualize the role of anxiety in children and adolescents with ASD, examining the research on treatments that have been found to be effective with this population can potentially provide further insight into this relationship between these two disorders. Due to the high prevalence rates and the severity of anxiety symptoms in children and adolescents with ASD, significant attention has been dedicated to researching effective treatments for this population (Kerns, Renno, Storch, et al., 2017). In this section, psychological and pharmacological treatments that have been proven to be effective with this population are explored.

Regarding psychological treatments, CBT has long been considered the gold-standard treatment for addressing anxiety symptoms in neurotypical children and adolescents (Kerns,

Renno, Storch, et al., 2017). Due to the long-standing success that CBT has had with improving anxiety symptoms in neurotypical youth, recent efforts have been made to modify or adapt this type of treatment to meet the unique needs of children and adolescents with ASD (Kerns et al., 2016; Kerns, Renno, Storch, et al., 2017; Walters et al., 2016). Children and adolescents with co-occurring anxiety and ASD often struggle with cognitive inflexibility, concrete thinking, communication deficits, executive functioning deficits, theory of mind deficits, perseveration, emotion regulation difficulties, and generalizing concepts across environments (Kerns, Renno, Storch, et al., 2017; Scattone & Mong, 2013). Due to these difficulties, it is necessary to modify the traditional CBT so that it can be effective for this population. Research has identified the following ways that traditional CBT can be modified to improve outcomes for children and adolescents with ASD and co-occurring anxiety: having parents more involved in treatment, incorporating more social skills and emotion regulation activities, utilizing visual aids, using worksheets, utilizing more multiple-choice questions as opposed to open-ended questions, incorporating technology that help guide individuals through coping skills, making sessions highly structured and predictable, flexibility in length and number of sessions (sessions may need to be shorter, which will increase the number of sessions), and increased flexibility/patience by the therapist (Kerns, Renno, Storch, et al., 2017; Scattone & Mong, 2013).

Efficacy research regarding the use of CBT to treat youth with co-occurring anxiety and ASD has yielded positive results, particularly with higher-functioning youth who have the verbal abilities necessary to engage in this type of treatment (Storch et al., 2013; Storch et al., 2015; Sukhodolsky et al., 2013). Storch et al. (2013) and Storch et al. (2015) examined the effectiveness of CBT when compared to treatment as usual (TAU) when treating anxiety in children with high-functioning ASD. TAU is a term frequently used in research referring to the

treatment considered the standard practice in that particular discipline. In this population, TAU refers to pharmacological interventions and medication management, social skills interventions, special education services, and school counseling (Kerns, Renno, Storch, et al., 2017). Storch et al. (2013) examined 45 children between the ages of 7–11. Of these 45 participants, 21 were randomly assigned to the 16-week TAU treatment and the other 24 were assigned to the 16-week modified CBT treatment. For this particular study, the modified CBT program used was the Behavior Interventions for Anxiety in Children with Autism (BIACA). The BIACA was described as “a modular treatment approach that incorporates problematic anxiety and non-anxiety-based symptoms as treatment goals while considering barriers to working with children with ASD” (Storch et al., 2013, p. 135). Results from this study revealed that 75% of the sample administered the CBT-adapted treatment were responsive to treatment, and 29% saw a reduction in the severity of their anxiety symptoms. Results also indicated that 73% of the participants in the CBT group maintained their treatment progress at the 3-month follow-up and approximately 38% of the participants in this group achieved remission status for their anxiety disorder diagnosis (Storch et al., 2013). Concerning the group that received the TAU treatment, 14% of the participants were responsive to treatment, and 9% saw a reduction in the severity of their anxiety symptoms. Additionally, only 5% of the TAU group achieved remission status for their anxiety disorder diagnosis at the follow-up stage (Storch et al., 2013). These results suggest that the CBT-adopted approach was more effective at reducing anxiety symptoms than the TAU approach in higher-functioning children with ASD (Storch et al., 2013).

Storch et al. (2015) utilized a similar research design when analyzing the effectiveness of CBT when compared to TAU when treating anxiety in high-functioning adolescents with ASD. This study had 31 participants ages 11–16 years old. Sixteen of the participants were randomly

assigned to a 16-week modified CBT program and 15 of the participants were randomly assigned to a 16-week TAU program (Storch et al., 2015). This study also utilized the BIACA treatment program for the CBT group. Results from this study indicated that 68.8% of the participants in the CBT group were responsive to treatment, while 26.7% of the TAU group were responsive to treatment. Furthermore, 37.5% of the CBT group achieved remission status for their anxiety diagnosis at post-treatment follow-up, while none of the participants in the TAU group achieved remission status. It was also noted that the participants in the CBT group maintained their progress at the three-month follow-up. These results provide further evidence that CBT is an effective treatment modality for higher-functioning youth with ASD (Storch et al., 2015).

To take a closer look at the effects of CBT in treating anxiety in high-functioning youth with ASD, Sukhodolsky et al. (2013) conducted a meta-analysis that examined these effects. Overall, they identified 8 studies that met their inclusion and exclusion criteria and these studies had 469 participants in total. Similar to other studies in this area, Sukhodolsky et al. (2013) noted that there were several methodological limitations to their meta-analysis due to subject characterization, outcome assessments that were used across studies, and difference in how waitlist or TAU groups defined when they were used as control groups. Despite these limitations, Sukhodolsky et al. (2013) reported that their results demonstrated preliminary evidence suggesting CBT was more effective for treating anxiety symptoms with this population when compared to waitlist or TAU control groups. Further research is needed to address the methodological issues in this area of study and to provide further evidence for these conclusions (Sukhodolsky et al., 2013).

While many of the studies are focused on examining how CBT impacts the anxiety symptoms in youth with ASD, a study by Drahota et al., (2011) examined the effects of CBT on

the daily living skills of higher-functioning youth with co-occurring anxiety and ASD. Results from this study suggested that CBT was effective in helping their participants reduce their symptoms of anxiety and these participants also saw a significant increase in their daily living skills and overall levels of independence in these skills. Drahota et al. (2011) noted that these results suggest the severity of ASD symptoms may be further aggravated by co-occurring anxiety symptoms.

Research that has examined the effectiveness of CBT in youth with co-occurring anxiety and ASD has typically utilized higher-functioning (which is typically associated with IQ and verbal abilities) samples. One of the main reasons research has utilized this type of sample is because CBT is a form of psychotherapy that requires verbal communication and the cognitive abilities to understand the relationships among thoughts, behaviors, and emotions (Kerns, Renno, Storch, et al., 2017; Sukhodolsky et al., 2013). Due to this, children and adolescents with co-occurring anxiety and ASD considered lower functioning and/or nonverbal are typically not candidates for this type of treatment. Research on lower-functioning and nonverbal youth with ASD and co-occurring anxiety is extremely limited. Consequently, the research on effective treatment options for this population is extremely limited. In fact, the research in this area is so limited that Kerns, Renno, Storch, et al. (2017) found seven studies involving eight lower-functioning youth with co-occurring anxiety and ASD. When examining the results from the individuals in these studies, Kerns, Renno, Storch, et al. (2017) found that graduated exposure and positive reinforcement were the effective treatment interventions for these participants. Given the limited research in this area and with this population, Kerns, Renno, Storch, et al. (2017) reported that graduated exposure and positive reinforcement can be considered “probably

efficacious” (p. 202). This is still an area of research that warrants further investigation to continue to identify efficacious treatments for this population.

Similar to other areas of research, studies have shown that the clinical heterogeneity of ASD also had significant impact on psychopharmacology (Aishworiya et al., 2022; Popow et al., 2021; Stepanova et al., 2017). This heterogeneity complicates research and has led to inconsistent findings on what medications are safe and effective to use when attempting to manage symptoms of anxiety in children and adolescents with ASD. The U.S. Food and Drug Administration (FDA) has only approved two medications to use with this population (Aishworiya et al., 2022). Risperidone, which is approved for children who are over 5 years old, and Aripiprazole, which is approved for children ages 6–17 years old, are both atypical antipsychotics that have been shown to be effective in reducing irritability, aggression, and repetitive behaviors (Aishworiya et al., 2022).

The inconsistencies in psychopharmacology research have made it difficult for medication prescribers to attempt to target anxiety symptoms in children and adolescents with ASD. This is problematic, considering that a significant portion of youth with ASD are prescribed one or more psychotropic medications (Ritter et al., 2021). A systematic review by Ritter et al. (2021) examined the use of medications in this population by analyzing 16 studies on the topic that contained over 300,000 participants. Their systematic review showed that the rates of medication use in children and adolescents with ASD varied significantly across the 16 studies, ranging from 6.8% to 87% (Ritter et al., 2021). These rates have been increasing over time, and research indicates that psychopharmacology has become more of a first line of treatment despite findings suggesting that, in most instances, psychopharmacological interventions should be utilized either after psychological interventions have been attempted or

concurrent with psychological interventions (Aishworiya et al., 2022; Ritter et al., 2021). The increase in psychopharmacological interventions within this population is also concerning because many providers are prescribing medications for off-label use, which means these medications are being prescribed for different purposes than what the FDA approved (Aishworiya et al., 2022). One of the primary examples of this within this population is utilizing antidepressants, particularly selective serotonin reuptake inhibitors (SSRIs), to treat anxiety, repetitive behaviors, and OCD symptoms (Popow et al., 2021). While antidepressants are widely used with children and adolescents with ASD, research on this topic has been inconsistent, and there have been some studies showing that utilizing antidepressants to treat anxiety in this population can have negative effects (Aishworiya et al., 2022; Stepanova et al., 2017). These negative effects include increases in symptoms of hyperactivity, impulsivity, stereotypy, and insomnia (Stepanova et al., 2017). It has also been noted that individuals with ASD have reported more negative effects of SSRIs than neurotypical samples, which means that individuals with ASD may be at an increased risk for side effects of SSRIs (Stepanova et al., 2017). Due to the inconsistencies in this area of research, further investigation is warranted to ensure the safety and efficacy of psychopharmacological interventions with this population.

Assessing Anxiety in ASD

As mentioned earlier, one of the major limitations in this area of research is the lack of assessments that are validated and reliable for children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014; van Steensel et al., 2011; van Steensel et al., 2014; Vasa & Mazurek, 2015). In a comprehensive review of assessment measures, Grondhuis and Aman (2012) reviewed 60 articles and recorded what measures were being used to measure anxiety in children and adolescents with ASD. This review found that 36 different measures had

been used to assess anxiety in this population and found that most of these measures had not been validated for children and adolescents with ASD. In an effort to address this limitation and advance the research in this area of study, researchers have placed emphasis on identifying assessments that can be used to accurately assess anxiety in this population. By identifying assessments that are valid and reliable for this population, this could improve aspects such as early identification, further developing evidence-based treatment models, and treatment progress monitoring (Lecavalier et al., 2014). The following sections examine the assessments that have been reviewed in the research and have been found to be appropriate to use with children and adolescents with ASD.

Questionnaires

Questionnaires are the most frequently used method for assessing anxiety in children and adolescents, with and without ASD (Kerns, Renno, Storch, et al., 2017). Due to this, a significant amount of research has been dedicated to identifying which questionnaires can be used to accurately assess symptoms of anxiety in children and adolescents with ASD. One of the questionnaires that has been evaluated for use in this population is the Child and Adolescent Symptom Inventory-4th Edition Revised (CASI-4R). The CASI-4R is an informant-completed scale (parent and teacher scale) that can be used for children and adolescents between the ages of 5–18 years old (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). While this is a measure to assess for many different psychiatric disorders, there are 26 questions that utilize a four-point Likert scale to assess for anxiety disorders. In an evaluation of this measure, Lecavalier et al. (2014) found that 20 of the 26 questions regarding anxiety could be used to create the CASI anxiety scale. While research has shown that this scale has demonstrated good convergent validity, it noted that social anxiety was under-represented in this scale (Kerns,

Renno, Storch, et al., 2017; Lecavalier et al., 2014). Findings also suggest that further development is needed in assessing for anxiety symptoms in lower-functioning children and adolescents (Lecavalier et al., 2014). Overall, this has been deemed an appropriate outcome measure to use with children and adolescents with ASD as long as the aforementioned limitations are accounted for when using this measure (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014).

Another assessment measure that has been evaluated to use with children and adolescents with ASD is the MASC. This questionnaire is used to assess symptoms of anxiety in individuals ages 8–19 years old and has a self-rating form and a parent rating form (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). The MASC is a 39-item assessment that utilizes a four-point Likert scale to assess physical symptoms of anxiety, social anxiety, harm/avoidance, separation/panic, and total anxiety (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Research findings indicate that the MASC has acceptable internal consistency ratings, modest convergent validity ratings, and demonstrated acceptable treatment sensitivity (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Regarding limitations, an evaluation of this measure by Lecavalier et al. (2014) found that the MASC was highly dependent on language, which may limit its use with children and adolescents with communication deficits. Overall, research supports the use of this questionnaire as an outcome measure with children and adolescents with ASD as long as the language development is deemed adequate (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014).

A third questionnaire that has been evaluated to use with children and adolescents with ASD is the SCAS, a 44-item questionnaire that can be used with children and adolescents ages 7–14 years old (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2014;). This assessment is

available in self-report and parent-report formats and assesses the areas of separation anxiety, social anxiety, obsessive-compulsive, panic-agoraphobia, generalized anxiety, and physical injury fears (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2014). Evaluation of this assessment has shown acceptable internal consistency for the child and parent reports and moderate to strong agreement across subscales (Magiati et al., 2017). This measure also demonstrated good convergent validity, and strong specificity and sensitivity (Kerns, Renno, Storch, et al., 2017; Vasa & Mazurek, 2015). Like many of the other questionnaires, this assessment is highly dependent on language and may be more appropriate to use with higher-functioning children and adolescents who do not have language deficits (Kerns, Renno, Storch, et al., 2017). Research has determined that this questionnaire is appropriate to use with higher-functioning youth (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2014; Vasa & Mazurek, 2015).

The aforementioned questionnaires have been deemed appropriate to use with children and adolescents with ASD. The following assessments have been deemed potentially appropriate based on preliminary research. The first questionnaire in this section is the Screen for Child Anxiety-Related Disorders (SCARED). The SCARED is a 41-item assessment that utilizes a three-point Likert scale and has a self-report and a parent rating form (Lecavalier et al., 2014). The age range for the SCARED is 9–18 years old and the scores from this assessment are divided into categories of somatic/panic, social anxiety, separation anxiety, generalized anxiety, and school phobia (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014).

Regarding psychometric properties, the SCARED demonstrated moderate internal consistency and moderate convergent validity. However, there have been mixed findings about the treatment sensitivity and specificity (Kerns, Renno, Storch, et al., 2017; Lecavalier et al.,

2014; Vasa & Mazurek, 2015). These concerns about the treatment sensitivity and specificity require more research and this is the reason that this questionnaire has been labeled as potentially appropriate as an outcome measure for this population (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014; Vasa & Mazurek, 2015). Research findings also suggest that this questionnaire requires higher cognitive and language abilities, which may limit its use to higher-functioning youth with ASD (Lecavalier et al., 2014).

Another questionnaire that has been found to be potentially appropriate to use with children and adolescents with ASD is the Revised Child Anxiety and Depression Scale (RCADS). The age range for the RCADS is 9–18 years old and comes in a self-report form and a parent-report form (Lecavalier et al., 2014). The RCADS is a 47-item questionnaire that utilizes a 4-point Likert scale (Lecavalier et al., 2014). Of the 47 items, 36 measure anxiety symptoms in the areas of separation anxiety, social anxiety, generalized anxiety, panic, and OCD. Research has indicated that the RCADS has acceptable test-retest reliability, acceptable internal consistency, and modest convergent validity; however, there have been concerns related to interrater reliability and divergent validity that need further investigation (Kaat & Lecavalier, 2015; Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Due to these concerns, this questionnaire has been labeled as potentially appropriate to use with children and adolescents with ASD (Kaat & Lecavalier, 2015; Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). It also should be noted that this assessment has been found to be useful as an outcome measure for children and adolescents with ASD and ID (Kaat & Lecavalier, 2015).

The Anxiety, Depression, and Mood Scale (ADAMS) is another questionnaire that has been evaluated for use with children and adolescents with ASD and deemed potentially appropriate. The ADAMS is a 28-item informant-rated assessment that utilizes a 4-point Likert

scale to assess symptoms related to anxiety and other mood aspects in individuals ages 10–79 years old (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Regarding the anxiety portion of this assessment, the ADAMS provides a Generalized Anxiety subscale and a Social Anxiety subscale (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Concerning psychometric properties, research indicates that variables such as internal consistency and test-retest reliability were at acceptable levels; however, the validity variables of this measure with children and adolescents with ASD needs further investigation (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). In addition to the uncertainty about the validity, this scale only provides information about generalized anxiety symptoms and social anxiety symptoms, which limits its usefulness in assessing the broad spectrum of anxiety disorders (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). The research on the use of this questionnaire with children and adolescents is very limited, and many of the validity variables need further investigation. Therefore, this measure has been labeled as potentially appropriate (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014).

The last questionnaire that has been deemed potentially appropriate for children and adolescents with ASD is the Autism Spectrum Disorders-Comorbidity for Children (ASD-CC). The ASD-CC is a 49-item parent-report questionnaire that can be used for youth ages 2–16 (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2014). This assessment contains subscales in the areas of worry/depressed, avoidant behavior, and repetitive behaviors (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2014). The subscales that measure aspects of anxiety have demonstrated moderate internal consistency, good convergent validity, and good discriminant validity (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2014). Due to its limitations in areas of anxiety that it assesses for, it has been determined that this questionnaire is

potentially appropriate as an anxiety screener for children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2014).

In addition to the questionnaires that have been found to be appropriate and potentially appropriate to use with children and adolescents with ASD, some questionnaires measure specific types of anxiety. An example is the Social Anxiety Scale for Children Revised (SASC-R). This questionnaire comes in a self-report form for youth ages 8–18. (Kerns, Renno, Storch, et al., 2017). The SASC-R has 22 items that assess symptoms of social anxiety, such as fear of negative evaluation and generalized and specific social avoidance and distress (Kerns, Renno, Storch, et al., 2017). While the research on using this questionnaire with children and adolescents with ASD is limited, existing findings suggest it has good internal consistency, adequate treatment sensitivity, and moderate convergent validity (Kaboski et al., 2015). Overall, research has determined that this questionnaire is appropriate to use with children and adolescents with ASD to assess for social anxiety (Kuusikko et al., 2008).

Another social anxiety measure that has been evaluated for the use with children and adolescents with ASD is the Social Worries Questionnaire (SWQ). The SWQ is a 10-item assessment available in a self-report form and a parent-report form and is used for youth ages 8–17 years old (Kerns, Renno, Storch, et al., 2017). Research findings have shown acceptable internal consistency and adequate treatment sensitivity; however, comparisons show weak relations between the self-report forms and the parent-report forms (Kerns, Renno, Storch, et al., 2017). This is an area that needs additional research to examine further these psychometric properties. Consequently, the SWQ has been deemed potentially appropriate to assess for social anxiety in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017).

Also, a number of questionnaires have been found to be not appropriate to use with this population. One of these assessments is the Revised Children's Manifest Anxiety Scale (RCMAS). Research has indicated that the yes/no response format does not allow for accurate assessment of the severity of the anxiety symptoms in children and adolescents with ASD (Lecavalier et al., 2014). Research has also indicated this measure has limited research as an outcome measure in randomized trials so there are reliability and validity concerns about this measure (Lecavalier et al., 2014). Additionally, there are concerns about whether the RCMAS actually assesses for symptoms of anxiety or if it is assessing for general distress that overlaps with symptoms of depression (Lecavalier et al., 2014). Dierker et al. (2001) analyzed discriminate accuracy of the RCMAS and found that this assessment did not discriminate between anxiety and depression.

Another questionnaire that has been identified as an outcome measure that is not appropriate to use with children and adolescents with ASD is the Nisonger Child Behavior Rating Form (NCBRF). This questionnaire has an Insecure/Anxious subscale and an Overly Sensitive subscale that assess for aspects of anxiety disorders; however, research has determined that these subscales do not adequately assess for symptoms of anxiety disorders and are therefore not appropriate to use as an anxiety outcome measure in this population (Lecavalier et al., 2014). Similar to the NCBRF, research indicates that the Child Behavior Checklist (CBCL) should not be used as an outcome measure with children and adolescents with ASD due to insufficient items that measure anxiety symptoms (Lecavalier et al., 2014). Finally, the last questionnaire that has been deemed inappropriate to use as an outcome measure with children and adolescents with ASD is the Baby and Infant Screen for Children with Autism Traits part II (BISCUIT). This measure has an Anxiety/Repetitive Behavior subscale; however, there are only 11 items that

measure symptoms of anxiety (Kerns, Renno, Storch, et al., 2017). Consequently, research has indicated that this measure may be useful as a screener but is too limited to use as an outcome measure (Kerns, Renno, Storch, et al., 2017).

The questionnaires that have been discussed above have been developed and validated for non-ASD populations and research has assessed whether these questionnaires are appropriate to use with children and adolescents with ASD. To date, the Anxiety Scale for Children-ASD (ASC-ASD) is the only questionnaire that has been developed specifically for children and adolescents with ASD (Rodgers et al., 2016). The ASC-ASD is an adapted version of the RCADS that includes additional items that incorporate characteristics of anxiety that are commonly seen in children and adolescents with ASD (Rodgers et al., 2016). These additional items were related to intolerance of uncertainty, phobias, and sensory anxiety (Rodgers et al., 2016). Overall, the ASC-ASD is a 24-item questionnaire available in self-report and parent-report forms for children and adolescents ages 8–16 years old (Kerns, Renno, Storch, et al., 2017). This measure consists of 4 subscales in the areas of Performance Anxiety, Uncertainty, Anxious Arousal, and Separation Anxiety (Kerns, Renno, Storch, et al., 2017). Research has indicated that the ASC-ASD has high internal consistency ratings, high test-retest reliability values, and high parent-child agreement (Kerns, Renno, Storch, et al., 2017; Rodgers et al., 2016). Additionally, the ASC-ASD has also demonstrated good convergent validity, discriminant validity, and content validity. Regarding limitations, it has been noted that this measure has yet to be tested with children and adolescents with ASD and co-occurring intellectual disability (Kerns, Renno, Storch, et al., 2017; Rodgers et al., 2016). More research is needed to determine if this questionnaire is appropriate to use with varying levels of intellectual functioning. Overall, this measure demonstrates strong psychometric properties and has been determined to be

appropriate to use with children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; Rodgers et al., 2016).

Clinician Rating Scales and Interviews

While questionnaires are the most frequently used method of assessment, clinician rating scales and interviews are considered more accurate (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009). In clinician rating scales and interviews clinicians are permitted to ask more in-depth questions that allow for clarification and a more detailed understanding of the anxiety symptoms (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009). Additionally, clinicians are also able to observe the behavior of the child or adolescent during the interview process, which provides the clinician with further behavioral observations that can aid in diagnosis and conceptualization (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009).

One clinician rating scale that has been evaluated for the use with children and adolescents with ASD is the Pediatric Anxiety Rating Scale (PARS). The PARS is a clinician-rated measure that can be used with children and adolescents ages 7 to 17 years old. For this assessment, the clinician conducts a semi-structured interview with the child and the parent and scores the anxiety symptoms according to the information provided (Lecavalier et al., 2014). The anxiety symptoms are assessed on seven dimensions: number, frequency, distress, avoidance, interference at home, interference outside the home, and level of physical symptoms (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Each of these dimensions is ranked by the administrator on a six-point Likert scale and the total score is added up at the end. Research on the psychometric properties of this assessment has found that the intraclass correlation and the test-retest reliability values were high but the internal consistency outcome scores were low (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). In regard to validity, research has

found partial support for convergent and divergent validity for assessing anxiety in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Additionally, it was noted that the interview portion of the assessment requires fluent language, which limits its use to children and adolescents who do not have communication deficits (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). The PARS has been deemed an appropriate measure to use with children and adolescents with ASD as long as the necessary steps are taken to ensure that language abilities are satisfactory to adequately participate in the assessment (Lecavalier et al., 2014).

The other clinician rating scale that has been evaluated to use with this population is the Children's Yale-Brown Obsessive-Compulsive Scale for Pervasive Developmental Disorders (CY-BOCS-PDD). This assessment is an adaptation of the original scale designed to be used with children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017). To achieve this adapted version, the compulsion checklist was included in the adapted version, but the obsession checklist was removed due to the cognitive and communication limitations that are common in this population (Kerns, Renno, Storch, et al., 2017). Additionally, repetitive behaviors that are common in ASD were added to the compulsion checklist. Research on psychometric properties for this measure for use with children and adolescents with ASD has yielded strong results (Scahill et al., 2006). More specifically, the interrater reliability and the internal consistency values were excellent, and the sensitivity to change levels were also strong (Scahill et al., 2006). Regarding validity, research has indicated that all of the validity measurements were modest (Scahill et al., 2006). Despite these strong psychometric properties, this measure has been criticized for a few reasons. The first is that this measure only assesses for symptoms of OCD, which limits its usefulness (Kerns, Renno, Storch, et al., 2017). Another reason this measure has

been criticized is that it is unclear if this measure is accurately assessing the presence of OCD without assessing for obsession variables (Kerns, Renno, Storch, et al., 2017). Therefore, this measure may be helpful for identifying OCD symptoms in children and adolescents with ASD, but further investigation is needed to determine if this assessment accurately assesses OCD constructs (Kerns, Renno, Storch, et al., 2017).

Research on semi-structured interviews has evaluated two measures that have been validated in neurotypical populations and two measures that have been adapted to ASD populations. The first semi-structured interview developed for neurotypical populations is the Anxiety Diagnostic Interview Schedule (ADIS), but it has been evaluated for use with children and adolescents with ASD. The ADIS is widely considered the gold standard for anxiety measures in the neurotypical population because it is the only interview specifically designed to assess multiple dimensions of anxiety disorders (Kerns, Renno, Storch, et al., 2017). While the ADIS is designed to be administered to the child and the parents at the same time, it can be administered separately if needed (Kerns, Renno, Storch, et al., 2017). While assessing for anxiety disorders, the ADIS also assesses for other disorders such as depression, ADHD, conduct disorder, and ODD (Lecavalier et al., 2014). The administrator rates the symptom severity and the functional impairments on a scale of 0 to 8 (0 = none, 8 = very severely disturbing/disabling), and a score of 4 (4 = definitely disturbing/ disabling) or higher is needed to receive a diagnosis in that domain. By design, the primary diagnosis would be the domain with the highest score (Lecavalier et al., 2014). Evaluations have shown that the ADIS demonstrated adequate validity and reliability in higher-functioning children and adolescents with ASD (Lecavalier et al., 2014). Despite the adequate levels of reliability and validity, the ADIS has been criticized for the length of the assessment and the time it takes to administer the assessment as instructed (Lecavalier et

al., 2014). While the assessment is thorough and typically produces valuable results, the time-consuming nature of this measure makes it difficult to use in clinical trials (Lecavalier et al., 2014). In addition to the lengthy administration times, research also found some variation in the parent ratings and the child/adolescent ratings, which needs to be monitored if using this measure in larger studies (Lecavalier et al., 2014). Additionally, the child needs to be able to participate in an interview, which requires higher verbal abilities; therefore, research has only evaluated this measure on higher-functioning youth (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Overall, research has supported the use of this measure with children and adolescents with ASD as long as the limitations are considered prior to administration (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014).

Another semi-structured interview designed and normed for neurotypical populations but has been evaluated to use with children and adolescents with ASD is the Kiddie Schedule for Affective Disorders and Schizophrenia in School-Aged Children (K-SADS). This semi-structured interview can be used for children and adolescents ages 6 to 18 years old and incorporates information from the child and the parent (Kerns, Renno, Storch, et al., 2017). While not strictly an anxiety measure, the K-SADS does have an anxiety scale that assesses multiple areas of anxiety and OCD (Kerns, Renno, Storch, et al., 2017). When using the K-SADS with a group of high-functioning children and adolescents, Zainal et al. (2014) found that this measure had excellent interrater reliability and modest evidence of convergent validity. In addition to these findings, it was also noted that the K-SADS is free to use and is easier to administer than the ADIS (Kerns, Renno, Storch, et al., 2017). Overall, research has determined that the measure is appropriate to use with high-functioning children and adolescents with ASD (Gjevik et al., 2010; Kerns, Renno, Storch, et al., 2017). More research is needed to determine if

this assessment is appropriate to use with lower-functioning individuals with communication deficits and intellectual disability (Gjevik et al., 2010; Kerns, Renno, Storch, et al., 2017).

While the ADIS and the K-SADS produced acceptable psychometric properties with children and adolescents with ASD, one of the limitations in these two measures is their inadequate differentiation of anxiety symptoms from the core symptoms of ASD (Kerns, Renno, Storch, et al., 2017). In an effort to account for this distinction and accurately capture the unique manifestation of anxiety symptoms in this population, the ADIS and the K-SADS were both modified from their original versions. The Autism Comorbidity Interview-Present and Lifetime Version (ACI-PL) is a modified version of the K-SADS that intends to differentiate between the symptoms of ASD and the symptoms of other disorders (Kerns, Renno, Storch, et al., 2017). The ACI-PL is a semi-structured parent interview that can be used with youth ages 5–17 years old (Kerns, Renno, Storch, et al., 2017). Research on this measure is limited, particularly concerning anxiety symptoms. In a study that examined the psychometric properties of this measure with children and adolescents with ASD, Leyfer et al. (2006) found that the ACI-PL had good interrater reliability, test-retest reliability, and concurrent validity for OCD diagnosis. Additional research is needed to further examine the psychometric properties for anxiety disorders (Kerns, Renno, Storch, et al., 2017; Leyfer et al., 2006).

The other semi-structured interview that has been modified in an effort to better account for the unique manifestation of anxiety in ASD is the Autism Spectrum Addendum to the Anxiety Disorders Interview Schedule (ADIS/ASA). This addendum was designed by Kerns, Renno, Kendall, et al. (2017) and the goal of this measure was to differentiate between the traditional anxiety symptoms and the more ambiguous or ASD-specific symptoms of anxiety. Due to the heterogeneity in ASD assessments, the objective for this addendum was to provide a

systematic approach for differentiating between these typical and atypical anxiety symptoms that are seen in this population (Kerns, Renno, Kendall, et al., 2017). This addendum is administered at the end of the ADIS and typically takes between 15–30 extra minutes to administer (Kerns, Renno, Kendall, et al., 2017). When evaluating the psychometric properties of this assessment, Kerns, Renno, Kendall, et al. (2017) found that this was a reliable measure of the traditional and the ambiguous symptoms of anxiety. In regard to validity, the results varied between the traditional and the ambiguous symptoms. For the traditional symptoms, the convergent and discriminant validity were fully supported; however, the results only partially supported the ambiguous symptoms (Kerns, Renno, Kendall, et al., 2017). In addition to the reliability and validity finding, the ADIS/ASA also demonstrated strong interrater agreement and test-retest reliability (Kerns, Renno, Kendall, et al., 2017). In their summary, Kerns, Renno, Kendall, et al. (2017) indicated that this was the only measure designed to assess for typical and atypical symptoms of anxiety that are seen in ASD. They also mentioned the strong initial psychometric properties of the measure but stated that further research needed to be completed to continue to examine the psychometric properties and continue to strengthen the systematic approach to assessing anxiety symptoms in this population (Kerns, Renno, Kendall, et al., 2017).

Currently, only one structured interview that has been evaluated for the purpose of using it with this population. Research that examines the psychometric properties of these types of measures with children and adolescents is limited. This measure, the Children's Interview for Psychiatric Syndromes-Parent Version (P-ChIPS) is a structured interview that is to be completed with a parent and can be used for youth ages 6–17 years old (Kerns, Renno, Storch, et al., 2017). Witwer et al. (2012) examined the reliability and validity of this measure with youth with ASD and found strong interrater reliability and internal consistency. Overall, Witwer et al.

(2012) indicated that this measure was appropriate to use with children and adolescents with ASD.

CHAPTER V: DISCUSSION

In their early descriptions of ASD, Leo Kanner and Hans Asperger noted that their subjects displayed an array of anxiety symptoms that spanned across multiple diagnoses (Frith & Mira, 1992; Kanner, 1943). Over the span of eight decades, the diagnostic criteria for ASD and anxiety disorders have changed, but the relationship between these diagnoses is a topic that is still being investigated today. Anxiety disorders are one of the most prevalent co-occurring disorders in children and adolescents with ASD and are one of the most common reasons for clinical referral in this population (Ghaziuddin, 2002; Simonoff et al., 2008). While research has identified that anxiety is highly prevalent in children and adolescents with ASD, there is still uncertainty about how the role of anxiety is best conceptualized concerning ASD. The uncertainty surrounding this conceptualization has significantly impacted multiple areas, such as assessment, diagnosis, presentation/manifestation, treatment, and research. The purpose of this clinical research project was to examine further the role of anxiety in children and adolescents with ASD with the goal of accurately defining this role and furthering research in this area. To further explore this role of anxiety in youth with ASD, a series of literature review research questions were proposed to help guide this clinical research project. These questions were:

1. How prevalent or significant is anxiety in children and adolescents with ASD?
2. How do symptoms of anxiety manifest in children and adolescents with ASD?
3. How is anxiety conceptualized, assessed, and treated in ASD?

Regarding the first question evaluated, while research has shown that anxiety disorders are among the most prevalent co-occurring disorders in children and adolescents with ASD, the prevalence rates across studies have varied significantly, ranging from 11% to 84% (White et al., 2009). To address this significant variability in prevalence rates, meta-analysis studies have been

conducted to try to establish more accurate estimates (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). Results from these meta-analysis studies showed the prevalence rate of anxiety disorders in children and adolescents was approximately 40%. The overall prevalence rate from the study by van Steensel et al. (2011) was 39.6% and the overall lifetime prevalence rate from the study by Hollocks et al. (2018) was 42%. In regard to specific anxiety disorder prevalence rates, results from each of the meta-analysis studies were fairly consistent as well. Specific phobia was found to be the most prevalent anxiety disorder in this population with prevalence rates from the meta-analysis studies ranging from 29.8% to 31% (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). The prevalence rates for the other anxiety disorders were as the following: OCD ranged from 17% to 22%, social anxiety disorder ranged from 16.6% to 20%, agoraphobia from 16.6% to 18%, generalized anxiety disorder from 15% to 26%, separation anxiety disorder from 9% to 21%, and panic disorder ranged from 1.8% to 18% (Hollocks et al., 2018; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011).

While these meta-analysis studies are helpful when attempting to establish more accurate prevalence rates in an area of study that has significant variability in results, concerns have been noted that these studies are only measuring the prevalence rates of constellations of anxiety symptoms that meet criteria for a diagnosis (Caamaño et al., 2013; Kerns et al., 2014; Muir, 2019; Wijnhoven et al., 2018). Furthermore, these studies may not be accounting for subclinical or atypical anxiety symptom constellations that may not fit into or reach diagnostic thresholds but still cause significant disruption or distress and can still impact the child or adolescents' daily functioning. Studies that examine subclinical anxiety symptoms have shown that between 66.3% and 81.4% of their samples of children and adolescents with ASD experience subclinical levels

of anxiety that still cause significant distress and impairment but do not meet the threshold for any one anxiety diagnosis (Caamaño et al., 2013; Wijnhoven et al., 2018). Research has also suggested that individuals with ASD may experience anxiety symptoms unique to ASD and are referred to as an atypical presentation. (Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017; Postorino et al., 2017; Wood & Gadow, 2010). These atypical anxiety symptoms do not align with *DSM* criteria and therefore are either not diagnosed in this population or are attributed to secondary reactions from core ASD symptoms (Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017). Kerns et al. (2014) showed that of the 63% of their sample that met the criteria for impairing anxiety symptoms, 17% of the sample met the criteria for traditional anxiety disorders, 15% met the criteria for impairing atypical anxiety symptoms, and 31% of the sample met criteria for both traditional and atypical anxiety symptoms. In sum, research on the prevalence of anxiety disorders in youth with ASD continues to produce varied co-occurring rates. While meta-analysis studies indicate that the true prevalence rate is around 40%, emerging research suggests that these studies may not account for subclinical anxiety symptoms or atypical anxiety symptoms that are unique to ASD (Caamaño et al., 2013; Hollocks et al., 2018; Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011; Wijnhoven et al., 2018). Efforts to incorporate these variables into assessments and future studies need to be made to achieve more accurate results for this population.

Question 2 focused on how symptoms of anxiety present in children with ASD. The large heterogeneity that exists across the ASD population makes it difficult to accurately define and describe how symptoms of anxiety manifest (Kerns, Renno, Storch, et al., 2017; Masi et al., 2017; Mottron & Bzdok, 2020; Postorino et al., 2017; van Steensel et al., 2011). While heterogeneity is an issue across virtually all mental health disorders, it is believed that the

variability across the ASD diagnosis is particularly high (Kerns, Renno, Storch, et al., 2017; Mottron & Bzdok, 2020). The shift to the autism spectrum model in the *DSM-5* seems to have contributed to the increased degree of heterogeneity in the ASD population (Mottron & Bzdok, 2020). While the ultimate goal of the transition to the autism spectrum model was to improve the accuracy of the ASD disorder, this change may have inadvertently created a larger degree of heterogeneity within this population (American Psychiatric Association, 2013a; Mottron & Bzdok, 2020). This increase in heterogeneity has had a significant impact on nearly all areas of ASD research, including the research on how anxiety symptoms manifest in children and adolescents with ASD.

Despite these challenges, research in this area has been able to identify factors that have had considerable influence on the way anxiety manifests in this population (Kerns, Renno, Storch, et al., 2017; Masi et al., 2017; Mottron & Bzdok, 2020; Postorino et al., 2017; van Steensel et al., 2011). Due to the impact that these variables have on the manifestation and conceptualization of anxiety symptoms within children and adolescents with ASD, these variables can also be considered risk factors for this population. The following variables have been identified as risk factors: sex of individual, age, intellectual functioning, ASD symptom severity, communication abilities, sensory reactivity, and other comorbid disorders such as ADHD, sleep disorders, and gastrointestinal problems (Al-Beltagi, 2021; Avni et al., 2018; Davis et al., 2011; Duvekot et al., 2018; Kerns et al., 2014, 2020; Kerns, Renno, Storch, et al., 2017; Khaledi et al., 2022; Lai et al., 2019; MacLennan et al., 2020; Mingins et al., 2020; Rodas et al., 2017; Salazar et al., 2015; So et al., 2021; Tarver et al., 2021; van Steensel et al., 2011; Varela et al., 2019; Wood & Gadow, 2010). While all of these factors have preliminary research

support, this is a relatively new area of study and additional research is needed to further support these findings.

When attempting to explain how symptoms of anxiety manifest in children and adolescents with ASD, another recent challenge identified is the traditional and atypical nature of the anxiety symptoms experienced in this population (Kerns & Kendall, 2012; Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017; Postorino et al., 2017; Wood & Gadow, 2010). As mentioned earlier, the traditional anxiety symptoms align with classic anxiety symptoms outlined in the *DSM* and the atypical symptoms are more unique to ASD. In one of the prominent studies about this topic, results showed that 63% of their sample met criteria for impairing anxiety symptoms (Kerns et al., 2014). Of the 63% who met criteria for impairing anxiety symptoms, 17% presented with traditional anxiety symptoms, 15% presented with atypical anxiety symptoms, and 31% presented with both.

Since research has supported the occurrence of traditional and atypical anxiety symptoms in this population, it is important to consider these variables as well when attempting to explain how anxiety manifests in this population. Despite the challenges associated with this area of study, research has been able to identify physiological/somatic, cognitive, and behavioral ways that traditional and atypical anxiety manifests in this population (Kerns, Renno, Storch, et al., 2017). Regarding the physiological/somatic manifestation of traditional anxiety, the symptoms include any of the following: increased arousal, increased heart rate, sweating, shakiness or restlessness, feeling overwhelmed or tearful, crying or screaming, sleep disturbances, eating disturbances, and anxious facial/body expressions (Kerns, Renno, Storch, et al., 2017). To date, no studies have investigated the physiological/somatic manifestation of atypical anxiety symptoms. This area needs to be studied due to the significant prevalence of these types of

anxiety in this population (Kerns, Renno, Storch, et al., 2017). Concerning the cognitive manifestation of traditional anxiety, symptoms include cognitive distortions and perseverations. Research has not identified any consistent cognitions for atypical anxiety symptoms (Kerns, Renno, Storch, et al., 2017). Atypical anxiety is a relatively new concept, and this population's cognitions are often difficult to interpret. This is also an area that needs further research. For behavioral manifestations of traditional anxiety, symptoms include attempting to escape from or avoid situations, seeking reassurance and trying to distract themselves from the source of anxiety. For behavioral manifestations of atypical anxiety, symptoms can include increased repetitive and/or ritualistic behaviors, sensory-seeking behaviors, and challenging behaviors (Kerns, Renno, Storch, et al., 2017). Practitioners need to assess for these symptoms when working with this population to ensure that they are accurately diagnosing and assigning appropriate treatments.

Another factor that has impacted the manifestation of anxiety in children and adolescents with ASD is the COVID-19 pandemic (Genova et al., 2021; Güller et al., 2021; Milea-Milea et al., 2023; Mutluer et al., 2020; Pai et al., 2022; Pecor et al., 2021; Vasa et al., 2021). The COVID-19 pandemic lasted over three years and research suggests that the pandemic had a greater negative impact on children and adolescents with ASD when compared to neurotypical children without ASD (Milea-Milea et al., 2023; Pai et al., 2022). This time was particularly challenging for this population because it significantly disrupted their daily routines. It is estimated that 59% of children and adolescents with ASD experienced worsening or new psychiatric symptoms during the COVID-19 pandemic, with anxiety symptoms being the most frequently reported (Milea-Milea et al., 2023; Pai et al., 2022; Vasa et al., 2021). These increased psychiatric symptoms led to increases in aggressive and maladaptive behaviors, hyperactivity,

repetitive/stereotyped behaviors, sleep difficulties, and change in appetite (Genova et al., 2021; Güller et al., 2021; Milea-Milea et al., 2023; Mutluer et al., 2020; Pai et al., 2022; Pecor et al., 2021; Vasa et al., 2021). Researchers estimate that roughly 78% of these youth experienced disrupted educational and therapeutic services when schools closed down and many parents expressed that their child struggled the most during these periods of interrupted services (Genova et al., 2021). While the COVID-19 pandemic was difficult for children and adolescents with ASD, research indicates that it was a challenging time for parents/caregivers of these youth as well (Milea-Milea et al., 2023). Parental stress levels increased by approximately 43% and these parents reported a lower quality of life during the pandemic (Pecor et al., 2021). Research will need to continue to study the effects that the COVID-19 pandemic had on the children and adolescents with ASD and their families to better understand how to address it therapeutically.

To understand how the role of anxiety is best conceptualized, assessed, and treated in children and adolescents with ASD, it is important to first understand the limitations that exist in this area of study and how they impact the research. The large heterogeneity that exists within this population continues to be identified as a limitation in this area (Kerns, Renno, Storch, et al., 2017; van Steensel et al., 2011). Regarding research, the literature has identified that methodological differences across studies can further contribute to the degree of heterogeneity within this population. There is no gold-standard assessment that accurately assesses anxiety in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014; van Steensel et al., 2011; van Steensel et al., 2014; Vasa & Mazurek, 2015). Many of the measures utilized in research studies have not been validated for the ASD population, do not account for overlap in symptomatology, and do not accurately assess for the atypical anxiety symptoms present in a significant portion of this population (Kerns, Renno, Storch, et al., 2017;

Lecavalier et al., 2014; van Steensel et al., 2011; van Steensel et al., 2014; Vasa & Mazurek, 2015). There are also concerns about whether children and adolescents with ASD and other respondents can accurately convey their symptoms of anxiety, which impacts the reliability of the measures that are used (Kalvin et al., 2020; Kerns, Renno, Storch, et al., 2017). Sample ascertainment, composition of control groups, and how variables are defined and operationalized across studies are also limitations that exist in this area of study (Kerns et al., 2014; Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Rice et al., 2012). Altogether, these limitations have significant influence on the research in this area and need to be addressed to advance research and further the understanding of the role of anxiety in children and adolescents with ASD.

Regarding Question 3, the number of limitations that exist within this area of research makes it difficult to formulate an accurate conceptualization of the role of anxiety in youth with ASD. Despite these challenges, some attempts to provide a conceptualization of the role of anxiety in children and adolescents with ASD have been made. Wood and Gadow (2010) created a conceptualization model in hopes of providing a guide for future research. This unidirectional model outlined how different ASD-related stressors created anxiety and mood dysregulation symptoms, which then have negative effects on the individual. The ASD-related stressors include social confusion or the unpredictable nature of social interactions, peer rejection, and bullying due to ASD symptoms, prevention from/punishment for engaging in repetitive behaviors or interests, and negative sensory experiences. These ASD-related stressors can either create symptoms of social anxiety or they can create symptoms of other anxiety disorders, depression, or other negative affectivity symptoms. Anxiety and/or other mood dysregulation symptoms can result in increased social avoidance, increased severity of ASD symptoms, increased maladaptive

behavioral problems, and increased personal distress or reduced quality of life (Wood & Gadow, 2010). Wood and Gadow (2010) stated that anxiety may either be a consequence of ASD symptoms, a mediator or moderator of ASD symptoms severity, or a proxy of ASD symptoms.

Kerns and Kendall (2012) proposed a series of questions that allowed them to explore the nature of the relationship between anxiety and ASD. These questions helped determine whether anxiety in ASD was better conceptualized as a part of the ASD diagnosis, a true comorbid condition, or if it was a novel or unique presentation of anxiety. Kerns and Kendall (2012) concluded that while prevalence rates of anxiety in ASD are high, anxiety is not universal in all individuals with ASD. This supports the notion that ASD and anxiety are likely separate, co-occurring disorders rather than anxiety being part of the ASD diathesis (Kerns & Kendall, 2012). When investigating whether anxiety in ASD is better conceptualized as a true comorbidity or a syndrome unique to ASD, Kerns and Kendall (2012) reported mixed findings and indicated that there is currently evidence supporting both possibilities. Advancements in assessment measures are needed to produce an accurate conceptualization (Kerns & Kendall, 2012). In addition to assessment limitations, methodological differences across the research in this area is also a major limitation and a coordinated effort is needed to advance the conceptualization of the role of anxiety in ASD (Kerns & Kendall, 2012).

When reviewing psychological interventions, research has shown that modified CBT has yielded positive results for higher-functioning youth that have the verbal abilities necessary to engage in this type of treatment (Storch et al., 2013; Storch et al., 2015; Sukhodolsky et al., 2013). Research on lower-functioning youth with ASD and co-occurring anxiety is extremely limited, but available research has shown that treatment interventions such as graduated exposure and positive reinforcement have yielded positive results (Kerns, Renno, Storch, et al., 2017).

Further research on effective psychological interventions in treating anxiety in lower-functioning youth with ASD is also needed. Regarding psychopharmacological interventions, research has shown that as much as 87% of children and adolescents with ASD are prescribed medication (Ritter et al., 2021). For this population, many providers are prescribing off-label medications that are not FDA approved to address anxiety symptoms (Aishworiya et al., 2022). The most common medication prescribed to address anxiety symptoms in this population is antidepressants, particularly SSRIs (Popow et al., 2021). While antidepressants are widely used in this population and have been found to be effective for some youth with co-occurring anxiety and ASD, research has indicated that these medications have negative effects for a significant portion of this population (Aishworiya et al., 2022; Stepanova et al., 2017). This area warrants more research, especially with the evidence of these negative effects on a large percentage of the population.

Assessments utilized to measure symptoms of anxiety in children and adolescents with ASD are limited (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014; van Steensel et al., 2011; van Steensel et al., 2014; Vasa & Mazurek, 2015). This limitation is recognized throughout the research, and efforts to address this issue are already underway (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Some studies have examined the assessments that have been used to measure anxiety symptoms in youth with ASD and have evaluated how appropriate they are to use with this population (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Regarding general questionnaires, the Child and Adolescent Symptom Inventory-4th Edition Revised (CASI-4R), the MASC, and the SCAS have all been deemed appropriate to use with this population as long as the specific considerations for each assessment are accounted for (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). The SCARED, RCADS, the

ADAMS, and the Autism Spectrum Disorders-Comorbidity for Children (ASD-CC) have been deemed potentially appropriate to use with this population because additional research is needed for them to be deemed appropriate (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Regarding questionnaires that measure for symptoms of specific anxiety disorders, the Social Anxiety Scale for Children Revised (SASC-R) has been deemed appropriate to use to assess social anxiety symptoms in this population, and the SWQ has been deemed as potentially appropriate to assess social anxiety symptoms in this population (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). The Anxiety Scale for Children-ASD (ASC-ASD) is, to date, the only anxiety questionnaire that has been specifically developed for children and adolescents with ASD. Additional research is needed to determine if this assessment is appropriate to use with youth with intellectual disabilities.

In regard to clinician rating scales, the PARS has been the only measure that has been deemed appropriate to use with children and adolescents with ASD (Lecavalier et al., 2014). The Children's Yale-Brown Obsessive-Compulsive Scale for Pervasive Developmental Disorders (CY-BOCS-PDD) was deemed potentially appropriate but further research is needed (Kerns, Renno, Storch, et al., 2017).

Concerning semi-structured interviews, the Anxiety Diagnostic Interview Schedule (ADIS) and the Kiddie Schedule for Affective Disorders and Schizophrenia in School-Aged Children (K-SADS) have been found to be appropriate to use with this population as long as proper considerations are taken (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Early studies on the Autism Comorbidity Interview-Present and Lifetime Version (ACI-PL) and the Autism Spectrum Addendum to the Anxiety Disorders Interview Schedule (ADIS/ASA) have shown that these measures may be appropriate to use with this population, but further research is

needed to ensure these findings (Kerns, Renno, Storch, et al., 2017; Leyfer et al., 2006). The Autism Spectrum Addendum to the Anxiety Disorders Interview Schedule (ADIS/ASA) is the only measure that has been designed to assess for typical and atypical symptoms of anxiety that are seen in children and adolescents with ASD (Kerns, Renno, Kendall, et al., 2017). Only one structured interview, the Children's Interview for Psychiatric Syndromes-Parent Version (P-ChIPS), has been evaluated for use with this population. This measure was deemed appropriate for this population (Witwer et al., 2012).

Areas of Future Research

Research on the co-occurrence of anxiety in children and adolescents with ASD has surged over the past two decades and continues to garner significant attention every year (Vasa et al., 2017). While research on this topic continues to be conducted, the current limitations that exist within this area of study are substantial and are significantly limiting progress (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). For the research to continue to advance, the following areas need to be prioritized in future research.

Research teams have been seemingly working parallel to each other and have done very little to coordinate their efforts (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). Failure to coordinate efforts typically limits the degree to which meaningful advancements can be made in relation to time and can produce widespread variability in results that are difficult to build upon (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). To address this issue, research groups need to work together to coordinate their efforts and begin to outline universal parameters that can guide future research. One of the parameters that needs to be addressed consists of the methodological differences that exist within this area of research (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). This

includes variables such as the way in which diagnostic criteria are operationalized, defined, and applied in studies; the assessments used to measure symptoms; and the way in which samples and control groups are ascertained and composed (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017).

Another area needing further research is assessments for measuring symptoms of anxiety in children and adolescents with ASD. Within the assessment domain, the most pressing matter is identifying or creating anxiety measures that are validated to use with children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). These assessments need to be able to differentiate between the overlapping symptoms of ASD and anxiety as well as accurately assess for the atypical anxiety symptoms that are unique to ASD (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). Another priority within the assessment domain is to develop objective measures of anxiety, such as physiology or behavior-based assessment (Vasa et al., 2017). These types of assessments can be used in conjunction with self-report and other-informant measures that have historically been inaccurate and unreliable. It is believed that these types of objective measures would produce more reliable indicators of anxiety (Vasa et al., 2017). Research on physiological measures could also establish the mechanisms that underpin anxiety in this population.

The majority of the research on the co-occurrence of anxiety in children and adolescents with ASD has been conducted on what is termed as higher-functioning youth who are verbal and have IQ scores that are average or higher (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). Therefore, very little is known about the anxiety in youth with below average IQ scores and/or nonverbal/minimally verbal abilities. Future research should focus on examining the anxiety in youth with ASD that have co-occurring intellectual disability and/or

nonverbal/minimally verbal abilities (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017). This future research should also focus on finding evidence-based treatments that are effective for this population (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017).

Another area that warrants additional research is how various ASD characteristics moderate the presentation and manifestation of anxiety (Vasa et al., 2017). These characteristics include sensory sensitivities, atypical anxiety symptoms, cognitive rigidity, intolerance of uncertainty, emotion regulation, and social motivation (Vasa et al., 2017). While there is preliminary research into these characteristics, more research is needed to support the findings.

Future research on psychopharmacology for this population is also needed (MacNeil et al., 2009; Vasa et al., 2017). Research findings have been inconsistent. However, there has been growing evidence in more current research suggesting medications that are commonly prescribed to manage anxiety symptoms in this population have significant negative effects (Aishworiya et al., 2022; MacNeil et al., 2009; Stepanova et al., 2017; Vasa et al., 2017).

Finally, while neurobiology components are not within the scope of this clinical research project, it is a growing body of research that can contribute to other research on anxiety in youth with ASD. Linking neurobiological findings to behavioral and clinical findings is key to fully understanding how the role of anxiety is conceptualized in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009; Vasa et al., 2017).

Clinical Implications

It is important for mental health professionals to know how to properly assess, identify, diagnose, and appropriately treat symptoms of anxiety in youth with ASD. When assessing for anxiety symptoms in children and adolescents with ASD, the assessments should be as

comprehensive as possible. These comprehensive assessments should be multimodal and should include multiple informants. Where possible, assessments should include the following items: (a) anxiety assessment measures, (b) direct observation, (c) and clinical interview. The anxiety assessment measures should include self-report (if the child is able to complete self-reports) and other-informant reports (parent/caregiver and teacher reports). A combination of questionnaires, clinician rating scales, and structured interviews can be used, but it should be remembered that clinician rating scales and semi-structured/structured interviews typically provide more in-depth information because they involve observations and/or allow for additional follow-up. When using anxiety rating scales, it is important to use measures that have been validated for this population. For questionnaires, the Child and Adolescent Symptom Inventory-4th Edition Revised (CASI-4R), the MASC, the SCAS, the Social Anxiety Scale for Children Revised (SASC-R), or the Anxiety Scale for Children-ASD (ASC-ASD) should be used (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). When using clinician rating scales, the PARS should be used (Lecavalier et al., 2014). When using semi-structured interviews, the Anxiety Diagnostic Interview Scale (ADIS), the Kiddie Schedule for Affective Disorders and Schizophrenia in School-Aged Children (K-SADS), or Autism Spectrum Addendum to the Anxiety Disorders Interview Schedule (ADIS/ASA) should be used (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). The ADIS/ASA is the only measure designed to measure both typical and atypical symptoms of anxiety (Kerns, Renno, Kendall, et al., 2017). For structured interviews, the Children's Interview for Psychiatric Syndromes-Parent Version (P-ChIPS) should be used (Witwer et al., 2012). These particular measures should be used because research has deemed them appropriate for children and adolescents with ASD.

It should be noted that the majority of these anxiety assessments have only been validated for higher-functioning youth so using these measures with lower-functioning youth should be done with caution. For lower-functioning youth who have lower IQ scores and lower verbal abilities, it may be more beneficial to use other-informant reports or measures that include an observation component. Furthermore, youth with ASD often struggle with alexithymia so attempting to rank their symptoms on rating scales with numbers may be difficult (Kinnaird et al., 2019). It may be beneficial to utilize visual aids when administering rating scales to these youths to make the numbers more meaningful (MacNeil et al., 2009). Finally, physiological measures are in the early stages of development for use with children and adolescents with ASD. It is recommended that researchers and practitioners stay up to date on these developments and utilize these measures when they become available. Physiological measures are objective measures that can help lead to more accurate identification of anxiety symptoms in this population (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009).

Direct observations are another form of assessment recommended in this population. Where possible, direct observations should be conducted across a variety of settings to examine the potential changes in behavior across environments. Observations are particularly helpful because they can provide an abundance of information about the child that is hard to replicate outside of their everyday environments (MacNeil et al., 2009). During observations, researchers and practitioners should look for behavioral cues that may indicate the presence of anxiety. Since many children and adolescents with ASD struggle to accurately describe their emotions, observable changes in behavior may be better indicators of anxiety. During observations, behaviors such as avoidance, withdrawal, aggression, tantrums, fleeing, irritability/restlessness, refusing to participate, crying, somatic complaints, and lack of appetite are among some of the

potential indicators of anxiety in children and adolescents with ASD (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009). It may be helpful to conduct a functional behavioral assessment as part of these observation periods to help identify the antecedents and consequences that are contributing to or maintaining these behaviors and guide treatment as well (MacNeil et al., 2009).

The last part of the assessment process is the clinical interview. When assessing for anxiety symptoms in youth with ASD, the clinical interview may be one of the most important aspects of the assessment process. When conducting a clinical interview with children and adolescents, it is typically beneficial to conduct the interview with the child/adolescent and the parents/caregivers (Kerns, Renno, Storch, et al., 2017; MacNeil et al., 2009). This allows the researcher or practitioner to gain the perspective of the child/adolescent and the parents/caregivers. If it is believed that conducting a joint clinical interview will be problematic, separate interviews can be conducted. During a clinical interview, the researcher or practitioner should consider factors such as age, developmental and intelligence levels, and communication abilities (MacNeil et al., 2009). These are all factors that influence how the interview should be conducted. It is the responsibility of the researchers or practitioners to modify the clinical interview format to meet the needs of each child and adolescent. Content and questions may need to be modified for young children, youth with intellectual disability, or nonverbal or minimally verbal youth. For the youth with these characteristics, it may be necessary to utilize forced choice rather than open-ended questions (MacNeil et al., 2009). Resources such as visual aids, drawing supplies to help better illustrate their thoughts and emotions, and toys to gauge their thoughts and emotions through play may all be helpful in better understanding symptoms of anxiety in this population (Kerns et al., 2016). It is important that information regarding

developmental history, family history, psychiatric and medical history, educational history, previous mental health treatment, and current level of functioning is thoroughly assessed during the clinical interview (MacNeil et al., 2009). It is also important to assess for traditional and atypical symptoms of anxiety. For atypical anxiety, researcher and practitioners should inquire about worries/fears about disrupted routines or fears about not having access to special interests, unusual fears, social fears that are not related to social rejection, and compulsive/ritualistic behaviors that do not meet criteria for OCD (Kerns et al., 2014). It is also important to remember how factors such as sex of individual, age, intellectual functioning, ASD symptom severity, communication abilities, sensory reactivity, and other comorbid disorders can impact the presentation of anxiety symptoms in this population (Al-Beltagi, 2021; Avni et al., 2018; Davis et al., 2011; Duvekot et al., 2018; Kerns et al., 2014, 2020; Kerns, Renno, Storch, et al., 2017; Khaledi et al., 2022; Lai et al., 2019; MacLennan et al., 2020; Mingins et al., 2020; Rodas et al., 2017; Salazar et al., 2015; So et al., 2021; Tarver et al., 2021; van Steensel et al., 2011; Varela et al., 2019; Wood & Gadow, 2010). When assessing for symptoms of anxiety in children and adolescents with ASD, researchers and practitioners need to assess for triggers of anxiety, behavioral signs of anxiety, thoughts associated with anxiety, somatic complaints, sleep problems, appetite changes, and the presence of any effective and positive coping skills (MacNeil et al., 2009; Ozsivadjian et al., 2012).

When contemplating which therapeutic interventions to implement, it is important to consider the functioning level of the child or adolescent (Kerns et al., 2016; Walters et al., 2016). Verbal youth with average to above average IQ scores may be candidates for modified CBT (Storch et al., 2013; Storch et al., 2015; Sukhodolsky et al., 2013). Using therapeutic interventions from this framework require the practitioners to be patient, flexible, and creative in

the ways that the concepts are modified. Modified CBT sessions need to be structured and extra time should be reserved at the end of sessions to allow the child to practice the concepts/skills learned during the session (Kerns et al., 2016; Walters et al., 2016). When explaining concepts in session, practitioners should use multimodal teaching methods and should incorporate visual aids to help the individual learn the concepts (Kerns et al., 2016). It is important for the practitioners to remember that they will need to find ways to take abstract concepts and turn them into concrete learning objectives and activities (Kerns et al., 2016; Walters et al., 2016). Integrating the interests of the child or adolescents may also be helpful as it may help keep the individual engaged throughout the session and could help them better understand the concepts and skills if it is personalized to them (Kerns et al., 2016). Modified CBT for this population should also utilize social stories and social skills training should be integrated into sessions (Walters et al., 2016). Skills need to be modeled for these individuals and role plays may be beneficial to help with skill mastery (Walters et al., 2016). When teaching coping and problem-solving, it is important to teach simple skills that can be applied to a variety of situations (Kerns et al., 2016). Practitioners should also consider the role of the parents/caregivers in modified CBT. Parental/caregiver involvement is typically beneficial and allows the parents to learn ways in which they can better support the child or adolescent (Kerns et al., 2016; Walters et al., 2016). Having the parents/caregivers involved can also be helpful when establishing reinforcement programs. These programs can be developed and practiced in therapy sessions and then applied in other settings such as home and school (Kerns et al., 2016; Walters et al., 2016). Finally, practitioners should remember that modified CBT typically takes more sessions than traditional CBT and should account for this when treatment planning (Kerns et al., 2016; Walters et al., 2016).

For children and adolescents with ASD with lower IQ scores and/or are either minimally verbal or nonverbal, the options for treatment are very limited. The research in this area needs further development, and it is recommended that practitioners stay up to date with this research (Kerns, Renno, Storch, et al., 2017). Graduated exposure and positive reinforcement may be effective for youth in this population and integrating parents/caregivers into therapy sessions is highly recommended (Kerns, Renno, Storch, et al., 2017).

While recommendations on psychopharmacology interventions are not within the scope of this clinical research project, it is important for researchers and mental health professionals to be familiar with the different types of medications and how those medications impact children and adolescents with ASD. While researchers and mental health professionals should not make medication recommendations unless they have the proper credentials, they can refer them for a psychiatric evaluation to see if medications would be appropriate or beneficial. Researchers and practitioners should also be informed of medication history and medication changes and should be mindful of how treatment progresses in relation to the medication changes.

Recommendations

The limitations that exist within this area of research continue to restrict progress toward establishing a definitive conceptualization model regarding the role of anxiety in children and adolescents with ASD. Despite these limitations, it is still important to explore potential conceptualization models for this population in an effort to support future research. Based on this clinical research project review of the existing literature, some preliminary conceptualization ideas are suggested to depict the role of anxiety more accurately in children and adolescents with ASD (see Appendix A). Based on supporting research, this conceptualization idea incorporates components from previous conceptualization models while integrating new elements, such as

symptoms of traditional and atypical anxiety that have been observed in this population (Kerns et al., 2014; van Steensel et al., 2014; Wood & Gadow, 2010).

This conceptualization model begins with identifying the stressors the individual is experiencing in a stressors column consisting of two categories of stressors: traditional stressors and ASD-related stressors (see Appendix A). Traditional stressors for children and adolescents can include school stressors (e.g., grades, homework, deadlines, fear of school shootings), social stressors (e.g., making/developing friendships, dating, rejection, bullying, peer pressure, social media presence, cyberbullying), balancing responsibilities (e.g., school, work, extracurricular activities), conflict at home (e.g., difficult relationships with parents/siblings, abuse, parental separation/divorce, financial hardships, inadequate housing, food insecurity), challenges related to going through puberty, fear of the future, death of a loved one, and illness within the child or a loved one. This category includes the traditional stressors typically associated with *DSM* anxiety disorders (van Steensel et al., 2014). The other category in this column is ASD-related stressors. These ASD-related stressors include social stressors (stress related to theory of mind impairment, social confusion, unpredictable nature of social situations, peer rejection due to ASD symptoms), stress related to insistence on sameness, stress related to preventing repetitive behaviors or punishing for engaging in repetitive behaviors, stress related to sensory sensitivities, and stress related to change in routines (Kerns et al., 2014; van Steensel et al., 2014; Wood & Gadow, 2010). The clinician's first task would be to identify the types of stressors the client is experiencing.

These stressors are then mediated by the factors that have been found to influence significantly how anxiety manifests in this population. These factors include sex of the individual, age, intellectual functioning, severity of ASD symptoms, communication abilities,

sensory reactivity, and other comorbid disorders such as ADHD, gastrointestinal problems, and sleep disorders (Al-Beltagi, 2021; Avni et al., 2018; Davis et al., 2011; Duvekot et al., 2018; Kerns et al., 2014; Kerns et al., 2020; Kerns, Renno, Storch, et al., 2017; Khaledi et al., 2022; Lai et al., 2019; MacLennan et al., 2020; Mingins et al., 2020; Rodas et al., 2017; Salazar et al., 2015; So et al., 2021; Tarver et al., 2021; van Steensel et al., 2011; Varela et al., 2019; Wood & Gadow, 2010). The mediating factors then result in either traditional symptoms of anxiety, atypical symptoms of anxiety, or both traditional and atypical symptoms of anxiety (Kerns et al., 2014). These anxiety symptoms can then result in emotional dysregulation that can create an increase in one or more of the following areas: internalizing behaviors (e.g., increase in anxiety symptoms, depression symptoms, anger, irritability/restlessness, difficulty concentrating, and somatic symptoms), externalizing behaviors (e.g., increase in aggression, tantrums, disruptive behaviors, hyperactivity, impulsivity, and conduct problems), avoidance (e.g., avoidance of anxiety-provoking stimuli, social avoidance), and/or increase in ASD symptom severity (e.g., increase in repetitive behaviors, cognitive rigidity, insistence on sameness, and social communication deficits) (Bos et al., 2018; Kerns, Renno, Storch, et al., 2017; Wood & Gadow, 2010; van Steensel et al., 2014). This process can repeat, and the negative symptoms can continue to strengthen and evolve into formalized disorders. Similar to the model by Wood and Gadow (2010), the construction of this conceptualization model suggests that targeting anxiety symptoms in treatment could ultimately help reduce the severity of ASD symptoms as well.

This conceptualization model can serve as a guide for researchers and practitioners to increase their understanding of the relationship between anxiety and ASD in children and adolescents. Increasing understanding of this relationship will ultimately increase the ability to accurately diagnose symptoms of anxiety in this population so that these anxiety symptoms can

be effectively addressed in treatment. Researchers and practitioners attempting to utilize this conceptualization model should integrate the information from this model into their comprehensive assessment that includes anxiety assessment measures, direct observations, and clinical interview.

When administering anxiety assessment measures to children and adolescents with ASD, it is important to select measures that assess for traditional stressors and ASD-related stressors. For traditional stressors, any of the measures that have deemed appropriate to use with this population can be used. It is recommended that a combination of rating scales be used in order to get a thorough assessment of anxiety symptoms that may be present. In order to assess for the ASD-related stressors, it is important to include the Autism Spectrum Addendum to the Anxiety Disorders Interview Schedule (ADIS/ASA) in the assessment battery, as it currently the only measure that assesses for traditional and atypical symptoms of anxiety (Kerns, Renno, Storch, et al., 2017; Lecavalier et al., 2014). Researchers and practitioners should review items that the participant/patient endorsed prior to the clinical interview so they can follow up on these items.

During the direct observations, researchers and practitioners should also be looking for signs of traditional and ASD-related stressors and anxiety symptoms that are highlighted earlier in this section. These traditional stressors and anxiety symptoms align with the *DSM* diagnostic criteria for anxiety disorders and will be similar to the stressors and symptoms of anxiety that are observed in neurotypical children and adolescents without ASD. For the atypical stressors and anxiety symptoms, researchers and practitioners should look for idiosyncratic specific fears, anxiety related to change in routines or rigidity, anxiety related to sensory over-sensitivity, anxiety that results from social confusion, and anxiety that results from preventing the participant/patient from engaging in their circumscribed behaviors or interests (Kerns et al.,

2014; Kerns, Renno, Storch, et al., 2017; Wood & Gadow, 2010). Observable behaviors of these atypical stressors or anxiety symptoms may include increase in ritualistic/repetitive behaviors, increase in sensory behaviors, and increase in challenging/disruptive behaviors. Any observed traditional or atypical stressor or anxiety symptoms should be further explored during the clinical interview.

Similar to a traditional clinical interview, researchers and practitioners should start the clinical interview by gathering general information about the participant/patient such as developmental history, family history, psychiatric history, medical history, educational history, previous mental health treatment, trauma history, and current level of functioning. When assessing for anxiety symptoms, researchers should first consider the factors such as sex of the individual, age, intellectual functioning, severity of ASD symptoms, communication abilities, sensory reactivity, and other comorbid disorders such as ADHD, gastrointestinal problems, and sleep disorders. Research has identified that these factors influence the presentation and manifestation of anxiety in children and adolescents with ASD, and therefore are viewed as potential risk factors for this population (Al-Beltagi, 2021; Avni et al., 2018; Davis et al., 2011; Duvekot et al., 2018; Kerns et al., 2014; Kerns et al., 2020; Kerns, Renno, Storch, et al., 2017; Khaledi et al., 2022; Lai et al., 2019; MacLennan et al., 2020; Miggins et al., 2020; Rodas et al., 2017; Salazar et al., 2015; So et al., 2021; Tarver et al., 2021; van Steensel et al., 2011; Varela et al., 2019; Wood & Gadow, 2010). Researchers and practitioners should be mindful that the research on these identified factors is still currently being conducted so it is important to stay up to date with the current research. It should also be noted that these factors help identify trends within this population; however, a thorough assessment is still required for each individual. After the researchers and practitioners have considered these factors, they should follow up on

symptoms that were endorsed on the anxiety measures and any anxiety symptoms that were witnessed during the behavioral observations. After following up, the researchers and practitioners should assess for traditional and atypical symptoms of anxiety. When assessing for traditional symptoms of anxiety, the interview questions should be similar to the questions that would be asked in interviews with neurotypical children and adolescents without ASD. These questions should focus on identifying the duration and the intensity of the participant's/patient's anxiety symptoms to help create a timeline. These questions should also focus on identifying triggers of anxiety, the behavioral signs of anxiety, cognitive manifestations of anxiety, potential somatic complaints that are related to anxiety, sleep difficulties, changes in appetite, and the presence of any positive coping skills. Again, the traditional anxiety symptoms are aligned with the *DSM* diagnostic criteria so the questions should focus on identifying those types of symptoms.

After assessing for traditional symptoms of anxiety, researchers and practitioners should then assess for atypical anxiety symptoms that have been associated with this population (Kerns et al., 2014). Currently, there are four major atypical symptoms that need to be assessed for in this population. The first atypical anxiety symptom category is excessive worries around routines and restricted interests. This type of anxiety typically involves anticipatory worries related to any disruptions/changes to routines or daily schedules. This particular atypical anxiety category also involves excessive worries related to losing access/denied access to their special interests. Additionally, this atypical category also involves excessive worries about adherence to rules and rule breaking. The second atypical anxiety symptom category is unusual specific fears. Research has identified that some children and adolescents with ASD experience excessive worries about unusual things that do not normally prompt fear in other populations. Assessing for these

symptoms can be similar to assessing for specific phobias; however, the traditional specific phobias that are outlined in the *DSM* typically fall into categories that are common across populations. The unusual specific fears that are experienced by children and adolescents with ASD may be different for every participant/patient (Kerns et al., 2014; Mayes, Calhoun et al., 2013). The third atypical anxiety symptom category is social fearfulness. The anxiety symptoms in this atypical anxiety category are different than social anxiety disorder symptoms because these symptoms are not the result of social judgement worries. The social fearfulness symptoms occur from social confusion or feeling overstimulated in social situations. The overstimulation component can result from being confused about the rules or expectations in a social setting which can leave the individual feeling anxious, or the overstimulation can be the result of sensory sensitivities. Social environments typically involve more sources of sensory output or more intense sensory output which can be challenging for some children and adolescents in this population. These fears are frequently accompanied by increased somatic symptoms and are frequently associated with increased escape, avoidance, self-injurious, and aggressive symptoms (Kerns et al., 2014). The last atypical anxiety category is in regard to compulsive/ritualistic behaviors. The symptoms in this category differ from the symptoms of OCD because these behaviors in this atypical category are not typically preformed to prevent distress or prevent a feared outcome in the way that is observed in OCD. These symptoms are more related to the insistence on sameness in their environments (Kerns et al., 2014).

After the clinical interview is completed, the researchers and practitioners should consider all of the information collected through the assessment measures, direct observations, and clinical interview to form their conceptualization of the participant or patient. To aid with this conceptualization, the researcher or practitioner should determine whether the

participant/patient is experiencing traditional symptoms of anxiety, atypical symptoms of anxiety, or a combination of traditional and atypical symptoms. After this distinction is made, the researcher or practitioner should determine how these symptoms of anxiety are impacting the participant/patient. These anxiety symptoms could result in an increase in internalizing behaviors, externalizing behaviors, avoidance, and/or an increase in ASD symptom severity. Once the researcher or practitioner has accurately identified the symptoms of anxiety using this proposed conceptualization model and determined how these anxiety symptoms are impacting the participant/patient, then they can determine which type of treatment is appropriate.

Identifying anxiety symptoms in this population is imperative so it is important for researchers and practitioners to include specific questions about traditional and atypical symptoms of anxiety in their clinical interview. Symptoms of anxiety, particularly atypical anxiety symptoms are often missed, overlooked, or misattributed as symptoms of other disorders. If anxiety symptoms are not accounted for in this population, then they often times go untreated. Research has shown that untreated anxiety symptoms can lead to an increased risk of developing chronic anxiety issues as well as a variety of other negative outcomes such as depression, suicidal ideation, suicide attempts, substance use disorders, and increased ASD symptom severity (Adler Nevo et al., 2014; Hill et al., 2016; Kendall et al., 2004; Kerns, Renno, Storch, et al., 2017; Scott et al., 2022). Overall, failing to identify these anxiety symptoms could have significant impact on treatment progress and could be detrimental to the participant/patient. Identification of anxiety symptoms in children and adolescents with ASD can also help to advance the research in this area which can lead to an increased understanding of the nature of the relationship between anxiety and ASD in this population. This suggested conceptualization

model will require further exploration and development as research continues to develop and as the limitations that exist within this area continue to be resolved.

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Appendix A

Proposed Conceptualization of Anxiety Symptoms in ASD

