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Mothers' Views of Their Children's Anxiety in Autism: A Qualitative Approach

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ABSTRACT

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Children diagnosed with autism spectrum disorders (ASD), which is marked by severe
social disabilities, also present with higher rates of anxiety. Understanding the qualitative
symptoms that underlie anxiety in ASD may help to better characterize the overlap of ASD and
anxiety symptomology and suggest targeted treatment strategies. Twenty mothers with male
children diagnosed with high-functioning ASD were interviewed using a follow-up interview to
the SCAS parent rating scale, in order to better understand how mothers perceive their child's
anxious thoughts, behaviors and cognitions. All interviews were transcribed and thematic
analysis was used to analyze the results. Eight themes emerged from the analysis: first, anxious
symptoms in children with autism negatively impacts the whole family; second, anxiety
interferes with the child's life; third, mothers can identify anxiety by their child's anxious
behavior; fourth, children with ASD utilize coping strategies to reduce their anxiety; fifth,
children with ASD experience physiological symptoms with their anxiety; sixth, anxiety and
anxious thoughts go together; seventh, mothers can identify the etiology of children's anxiety;
and eighth, children's anxious thoughts are perceived by their mothers as reasonable.
Interventions for anxiety in ASD should consider the whole family system including education,
symptom reduction, and possible respite care.

ACKNOWLEDGEMENTS

"Always do what you are afraid to do."

Ralph Waldo Emerson

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Mothers' Views of Their Children's Anxiety in Autism: A Qualitative Approach

It is now well established that individuals with an Autism Spectrum Disorder (ASD) often present with a comorbid psychiatric diagnosis (Moseley, Tonge, Brereton, & Einfeld, 2011). This study was interested in exploring how a comorbid anxiety diagnosis presents in children and adolescents on the autism spectrum. Although efforts have been made to assess for anxious disorders in children and adolescents with ASD, current assessment measures have not been able to adequately capture the nuances of the anxiety presentation in this population (Kerns & Kendall, 2012).

The diagnosis of autism creates a significant burden on both the family and the community as a whole (Duarte, Bordin, Yazigi, & Mooney, 2005). These individuals often require a significant allocation of time, finances and emotional energy from those they interact with. On a variety of measures of wellbeing, designed to assess levels of stress, depression, pessimism, and quality of relationships, parents of children with ASD consistently report worse outcome compared to parents of typically developing children (Duarte et al., 2005). Mothers of children with ASD report more stressful events at work, at home, and in the social network as well as higher rates of arguments and avoided arguments in comparison to mothers of typically developing children (Smith, et al, 2010).

This pattern of lower levels of wellbeing holds true even when parents of children with ASD are compared to parents of children with other disabilities (Abbeduto et al., 2004). The divorce rate for parents with ASD is twice that of parents of children with other disabilities (23.5% vs. 13.8%) and remains at high rate throughout the child's adolescence and young

adulthood years (Hartley et al., 2010). Such results indicate the urgent need for research designed to help caregivers understand and cope with the impact of raising an ASD child.

It has been posited that the presence of comorbid symptoms in autism greatly reduce quality of life for both the individual and the family, and negatively impact social, and communication skills (Ghaziuddin, & Safar, 2008). Anxiety is recognized as possibly one of the most common co-occurring disorders in children on the autism spectrum, with reports stating the comorbidity rate to be as high as 84%, with most recent studies settling between 40-50% (White, Oswald, Ollendick, & Scahill, 2009). A literature review revealed that various studies have identified symptoms of anxiety in the ASD population negatively impacting social skills, increasing rates of aggression, and increasing risk-taking behavior (Pugliese, White, White, & Ollendick, 2013; South, Dana, White & Crowley, 2011; White, Schry & Maddox, 2012). Additionally, various studies have been done to explore how children and adolescents with autism present with specific anxiety diagnoses such as OCD, social anxiety disorder, generalized anxiety, and specific phobia. It is believed that a better understanding of how anxiety impacts ASD symptom presentation may help improve treatment, which could improve the quality of life for both the child and the family.

The main barriers to researching anxiety in autism are as follows: a) the presence of overlapping symptom criteria in the various anxiety disorder and autism (Kerns & Kendall, 2012); b) the lack of agreement in the literature regarding how to determine if a symptom is a product of anxiety or a core ASD deficit; and c) all current measures of anxiety have not been validated for the autistic population (White, Oswald, et al., 2009). Although work is being done to address these barriers more fully, there is a general consensus that a better understanding of how anxiety impacts symptom presentation in children and adolescents with autism may help -

improve quality of life, via more specialized treatment, intervention and support (Kerns &

Kendall, 2014).

Although efforts are being taken to understand anxiety in autism more fully, a review of

the literature indicates that research has mainly focused on using quantitative measures to

examine the relationship between anxiety and autism. The efforts that have been made to adapt

current quantitative measures of anxiety, designed for the typically developing population, to the

autistic are discussed in greater detail below. It should be noted that given the atypical

presentation of anxiety in autism, quantitative measures might not be sensitive enough to fully

capture the day-to-day presentation of anxiety in this population. As such, a qualitative approach

could provided greater detail and insight into understanding the relationship between anxiety and

autism.

Purpose of the Study

Mothers are in a unique position to observe their child's anxious behaviors, note subtle

differences in their physiological symptoms, and experience firsthand the impact of such

symptoms. Additionally, as the child's caretaker, she may be privy to her child's thought

processes as children may be more willing to share their thoughts with a trusted adult as opposed

to an unfamiliar researcher. Mother would also have the opportunity to observe how symptoms

evolved and changed overtime in response to various interventions and situations. As a caretaker,

mothers would also be able to describe the level of interference various anxiety symptoms can

cause on a day-to-day basis. The use of a semi-structured interview that utilizes open-ended

questions was specifically chosen in order to gather richly detailed narrative accounts. Their

report may serve to help with the development of better assessment measures and more targeted

treatments.

To be clear, the purpose of this study was not to clarify the separation between core ASD symptoms and anxiety, nor does it attempt to validate any anxiety measure for it's usefulness with diagnosing anxiety in the ASD population. The purpose was to explore how mothers of children with ASD interpret the anxious presentation in their high-functioning autistic children. Mothers' perceptions of how they understand their child's anxious symptoms may provide insights on the day-to-day presentation of anxious symptoms.

Significance of the Study

The intent of this study is to contribute to the overall knowledge base of how children and adolescents with high functioning ASD manifest anxiety symptoms. Specifically, this study focuses on mothers' perceptions and interpretations of their children's anxious symptoms. Current research has noted the lack of validated anxiety assessment measures for this population, as well as the diagnostic overlap leading to the lack of agreement of how to differentiate anxiety symptoms from autism symptoms. As parent report assessment measures are an important component of anxiety assessment in children and adolescents, understanding how mothers perceive their child's anxiety is an appropriate starting point for determining the complexities and nuances of differentiating and assessing anxiety symptoms in the high-functioning autistic population.

Research Design

A qualitative model was selected for this research study as this method allows the main focus of the research study to be on developing an understanding of a particular event or experience (Caelli, Ray, & Mill, 2003). Kostere and Percy (2008) noted that a qualitative research approach focuses on the actual experiences and perspectives of the participants and allows the content of the data to be driven by subjective descriptions. Since current quantitative measures of anxiety were validated on a typically developing population, mothers of children

with ASD may be forced to choose the "best option" instead of the most "accurate" option or not choose an option at all.

The qualitative data for this research study was gathered via a semi-structured interview was conducted with the participants. This type of interview format in qualitative research focuses on reflection, narration, and allows for flexibility associated with the types of questions posed to participants (Cooper & Ednacott, 2007). The semi-structured interview questions were used to obtain data that was specific to mothers' real world perspectives, and allowed for a breadth of data to be collected. The analysis of the data utilized thematic analysis procedures. Braun and Clark (2006) outlined a six-phase guide of how to use thematic analysis to identify themes within the qualitative data. This process is discussed in greater detail below.

Research Questions

To better understand anxiety in high-functioning ASD youth and how it presents on a day-to-day basis, this study posits the following research questions:

1. What themes emerge in mothers' descriptions of a child/adolescent's; emotions, actions, physiological arousal, and thoughts for a specific anxiety symptom or situation?
2. What do mothers attribute as being the source of their child's anxiety?
3. In what way do anxiety symptoms interfere with the child's/adolescent's life and family life on a day-to-day basis?
4. What methods do mothers observe their children using to cope with their anxiety?

Assumptions & Limitations

Several assumptions were made when designing this research study. First, it was assumed that the participants would be forthcoming about their experiences and observations. Second, it was assumed that anxiety is a co-occurring disorder in autism. Although this

assumption is becoming more widely accepted and supported by the research, without the availability of appropriate diagnostic tools, it difficult to validate this assumption.

Limitations will be explored in greater detail below, but it should noted that given the sample size, and the nature and purpose of qualitative research are not generalizable beyond the high-functioning, male autistic population. This study also cannot be assumed to represent the experiences of all mothers in similar situations. In addition, due to sampling constraints, participants of various cultural groups were not represented. As such, a diverse perspective could not be explored.

Role of the Researcher

In addition to having family members with autism or intellectual disabilities, the researcher has had six years of experience working with the developmentally delayed population. These experiences include working as a behavioral analyst for low functioning children on the autism spectrum, participating in graduate level education for clinical psychology, participating in a variety of practicum experiences involving individual and group therapy for children on the autism spectrum, and being apart as a multidisciplinary team designed to assess children with complex medical conditions. In all of these positions, the researcher has had the opportunity to conduct a variety of semi-structured interviews in order to assess, provide feedback, and initiate appropriate treatments. These experiences, combined with the personal experience of having a brother on the autism spectrum, have given the researcher the opportunity to understand the preconceptions and potential biases that exist about this population.

With qualitative research it is especially important for researcher to be aware of the potential biases that can be associated with the research they are conducting (Hoyt & Bhati, 2007). Potential biases can be assessed through peer consultation or through personal evaluation of one's own by point of view regarding the data that is being gathered. For this study, the

researcher made use of peer feedback by engaging in weekly meetings with two other researchers to discuss possible themes and biases. This process is discussed in greater detail during an explanation of the analysis process.

Literature Review

Autism Spectrum Disorders

Core diagnostic features. The term autism originates from psychiatrist Eugen Bleuler in 1911 and for some time the word "autism" was used to describe types of childhood-onset schizophrenia, as well as behaviors associated with extreme social isolation (Bleuler, 1950; Kunkel, 1920). Leo Kanner was the first to conceptualize autism as a separate condition. In 1943 he published a report in which he documented the behaviors and symptoms of 11 children with autism including: social isolation, impairment in language and communication, restricted interests, and intolerance for change (Kanner, 1943). To make autism clearly distinguishable from schizophrenia, Kanner argued that the symptoms in these children had been present since birth as opposed to developing later in life.

Later conceptualizations of the core diagnostic features of autism, characterized the disorder as a combination of impairment in social interaction, stereotyped patterns of behavior, and deficits in communication (American Psychiatric Association, 2000). Deficits in social interaction include lack of eye contact, failure to form relationships with peers, little or no emotional reciprocity, and a lack of pleasure in the happiness of others. Examples of the stereotyped patterns of behavior include the following: compulsive adherence to specific and nonspecific routines and rituals, such as demanding the same chair and position at the table during meals; odd motor behaviors like flapping and rocking; or a preoccupation with restricted patterns of interest such as a specialized interest area. Communication impairment can be manifested by a delay or lack of spoken language, an inability to sustain or start a conversation,

repetitive use of language and lack of social play. These impairments and abnormal functioning must be present before three years of age and cannot be better accounted for by a severe organic medical condition.

In addition to a diagnosis of autism, the Diagnostic Statistical Manual, 4th Edition, Text Revision (DSM-IV-TR) also created two additional diagnoses that were considered to be part of the autism spectrum: Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (American Psychiatric Association, 2000). Asperger's Disorder criteria included the impairments in social interaction and restricted/stereotyped behavior but did not include the communication deficits. PDD-NOS was a diagnosis used to describe individuals who presented with clear impairments in social interaction, verbal and/or nonverbal communication skills or when stereotyped behavior was present, but did not meet criteria for a specific diagnosis on the autism spectrum.

In the most recent publication of the DSM, the 5th edition outlined a few changes in the conceptualization of ASD. Instead of three broad domains of impairment (i.e., communication, social impairment, stereotyped/restricted patterns of behavior), only two broad domains were identified. A diagnosis of ASD now required deficits in the areas of social communication and social interaction, as well as the presence of repetitive behaviors and/or restricted interests. The social domain assessed for impairment in skills such as verbal communication, nonverbal communication, reciprocal social interaction and age-appropriate social skills. The deficits in the restricted and/or restricted domain are similar to the DSM-IV-TR, in that symptoms such as repeating phrases, rigid routines, stereotyped motor movements and circumscribed interests were all still within the domain.

With the new diagnostic criteria outlined by the DSM-5, clinicians are also expected to identify the severity of deficits present in each domain. Level 1 severity is used to describe a child who is "requiring support" and specifically states that this descriptor should be used if: "without supports in place, deficits in social communication cause noticeable impairments." A level 2 descriptor is used when a child is "requiring substantial support." For example, even with supports in place, marked impairment of social communication skills is still present. A level 3 is used to describe a child "requiring very substantial support." A child with very limited initiation and/or response in social situations would require a designation of level 3 support under this new classification process. This level system was designed in order to help clinicians describe the functioning level of child on the autism spectrum in order to assist with treatment planning. For the purposes of this study, the DSM-IV-TR diagnostic criterion was used, as the participants' children were diagnosed prior the publication of the DSM-5 in 2013.

Etiology. Dr. Mikle South of Brigham Young University often tells the story of working with a geneticist at Yale University. "Give me 10 kids with autism," the geneticist would say, "and I will give you 10 different genetic disorders." While there is much to be learned about the genetics behind an autism diagnosis, two things are very clear: the causes of autism are both multifaceted and complex.

Originally it was believed that the cause of autism was purely environmental, and specific blame was laid on a mother's failure to bond with her infant. For example, the term "refrigerator mother" was previously used to describe those mothers whose complete lack of appropriate nurturing of their infants in early childhood led to autism (Bettelheim, 1967). In contrast to this theory, Kanner proposed an alternative theory, which suggested that autism was present at birth.

The underlying implication of this theory was that nature - not nurture - played a key role in the development of autism.

Most recently, epigenetics has become a power player in the search for the causational factors of autism. An epigenetic trait is defined as " a stably heritable phenotype resulting in a chromosome without alterations in the DNA sequence" (Berger, Kouzarides, Shiekhattar, & Shilatifard, 2009). In other words, the study epigenetics is the study of how the environment may change the mechanisms that turn a specific gene expression on or off. One example of epigenetic research in autism is the study of possible multigenerational effects. Frans et al. (2013) found that men who had a daughter at the age of 50 or older were 1.67 times more likely to have a grandchild with autism, when compared to men who had a son when they were 20 to 24 years old. These results were significant even when controlling for birth year, age of the mother, family history of psychiatric disorders and highest family education level. There are many other areas of epigenetic research and autism: perinatal environmental exposures, transgenerational inheritance, and environmental susceptibility to name a few. As our understanding of the relationship between genetics and the environment grows, a more clear explanation of how autism is developed may be determined.

It should be noted that there have been controversies in recent years regarding the role of environmental factors and autism. The most infamous of these controversies involves vaccines. This controversy most likely originated from parent report that they noticed a deterioration of language and social skills in their child after he or she had received their diphtheria-tetanus-pertussis (DPT) vaccine. As these vaccines contained thimerosal, a preservative that contained mercury, parents came to blame mercury poisoning as the cause of their child's autism

(McCarthy, 2007). Although research was able to demonstrate the inaccuracy of this accusation, it continues to remain a heated issue among the general public (Offit, 2008).

Another controversy surrounding vaccines involved the mumps-measles-rubella vaccination (MMR). In this case, Andrew Wakefield published a paper in 1998, which reported several cases of children who developed symptoms of autism following receiving the MMR injection. The paper proposed a "leaky gut" theory, and suggested that the vaccine could cause inflammation in the intestines allowing toxins to enter the circulatory system and pass through the blood brain barrier. The toxins crossing the blood-brain barrier led to autism. It was later discovered that Wakefield deliberately falsified reports and the paper was retracted (retraction published February 2010; General Medical Council 2010). Although the vaccine controversy has been laid to rest in the scientific community (Offit, 2008), it remains a divisive issue for many parents and activists.

Prevalence. The most recent prevalence rate reported from the Center for Disease Control, estimated that an average of 1 in 68 children meet diagnostic criteria for an ASD (Center for Disease Control, 2015). Due to a variety of factors, the number of children diagnosed with the disorder has shown annual increases. Such factors include the widening of the criteria, increased recognition, and growing awareness among parents and professionals (Wing & Potter, 2009).

Of note, the widening of criteria specifically refers to the changes in the conceptualization of ASD that allowed children diagnosed with autism, even in the presence of other neuropsychiatric and medical disorders (e.g., such as epilepsy) and various levels of functioning (e.g., low vs. high functioning) (Fombonne, 2009). In comparison to when ASD was first conceptualized as including only the severely impaired, it is now believed that many

children on the autism spectrum do not have comorbid intellectual disabilities. From the DSM-IV (APA, 2000) it was estimated that only 40-50% of children diagnosed with ASD could also be classified as having intellectual disabilities. Although it should be noted that the rates of comorbid intellectual disability are higher in those diagnosed with an autistic disorder when compared to those diagnosed with Asperger syndrome or pervasive developmental disorder, not otherwise specified (Fombonne, 2009).

It was Shattuck (2006) who highlighted increased recognition as another possible explanation for rate at which ASD has increased; he found that there were simultaneous decreases in the rate of intellectual disability (ID) as the rates of ASD increased. The exact impact diagnostic substitution had on the rate of increase is unclear. Analysis of The California Department of Services database indicated that there was a substantial increase of the number of children diagnosed with ASD between the years 1992 – 2005 and as the rate of autism diagnoses increased, the rate of children diagnosed with "mental retardation" decreased (King & Bearman, 2009).

A wide variety of advocacy groups have also been responsible for increasing awareness and allocating funds for the diagnosis, treatment and research in the ASD population. Cure Autism Now, Autism Speaks, and the National Alliance for Autism Research are just few of the voluntary organizations founded by parents in order to raise awareness to the public about the ASD population. These groups have had a powerful impact on society at large, as they have been able to secure funding for research and impact public policy relating to treatment and support of individuals with ASD.

Assessment. Given the importance of early intensive behavioral intervention, there is good reason to attempt to diagnose autism at younger ages. Per Yeargin – Allsopp, et al., (2003)

diagnosis of autism typically occurs at the early elementary ages (5-7 years of age), although

substantial efforts have been made to diagnose children at even younger ages. Parents who

sought evaluations for their children typically reported that the first problems they noticed were

language delays, poor social skills, and unusual behaviors (de Alba & Bodfish, 2011). Of note,

most parents stated that they first began to notice such symptoms prior to two years of age,

which suggests that early diagnosis is possible (Chakrabarti, 2009).

In a recent systematic literature review three diagnostic instruments were identified as

having robust enough evidence to support their use: Childhood Autism Rating Scales (CARS),

Autism Diagnostic Interview- Revised (ADI-R) and Autism Diagnostic Observation Schedule

(ADOS) (Falkmer, Anderson, Falkner, & Horlin, 2013). The CARS is a questionnaire that can

be completed by either the clinician, teacher and or parent based on observations of the child's

behavior. The ADI-R is a standardized parent interview that asks questions about a child's

developmental history and current behavior. The interviewer codes the responses and an

algorithm is used to determine the significance of the reported symptoms. The ADOS is an

observational assessment measure with five different modules depending on the age and

functioning level of a child. The goal of the ADOS is to present a child with various social

situations and code how well they respond. It is generally expected that the ADOS and ADI-R

will be given together in order to provide the most efficacious assessment. Given that autism

symptoms can overlap with other psychiatric disorders (e.g., schizophrenia, selective mutism,

etc.) and medical conditions (e.g., Smith-Magenis Syndrome, Klinefelter Syndrome, etc.) having

a multi-disciplinary team involved in the diagnosis of the disorder is considered the most

efficacious (Jha, Sheth, & Ghaziuddin, 2007).

Common comorbid conditions. The complexity of diagnosing autism is also due to the presence with additional behavioral and psychiatric problems that commonly co-occur in the ASD population. Moseley, Tonge, Brereton, and Einfeld (2011) reported that comorbidity rates for children and adolescents with ASD were approximately 40%. Alternatively, Brereton, Tonge, and Pickles (2006) reported the comorbidity rates to be as high as 70% in the autistic population. Compared to children and adolescents with intellectual disabilities, individuals on the autism spectrum have higher rates of both psychiatric and medical comorbid diagnoses (Brereton, Tonge, & Pickles, 2006).

Cognitive delays are among the most common comorbid disorders associated with autism. A significant proportion of children diagnosed with ASD also have a comorbid diagnosis of intellectual disability (ID), with rates upwards of 50% (Centers for Disease Control, 2009). An ID diagnosis in conjunction with ASD is often associated with increased behavioral problems (Ben Itzchak, Lahat, Burgin, & Zachlor., 2008). Generally speaking, most children with an autism spectrum diagnosis have below average adaptive skills in comparison to their same age peers, regardless of the presence and/or severity of a comorbid intellectual disability (Charman et al., 2011).

Behavioral disorders are the other most common comorbid diagnoses associated with ASD, especially, attention deficit/hyperactivity disorder (ADHD). Although the DSM-IV-TR did not allow for the comorbid diagnosis of ADHD, recent research suggests that this may be the most common comorbid psychiatric diagnosis associated with ASD with the rates of cormorbid ADHD reported to be as high as 83% (Hartley & Sikora, 2009). The DSM-V allows for the co-diagnosis. There was much debate over whether or not the symptoms of ADHD were a part of the core presentation of ASD, but as that the DSM-V allows the comorbid diagnosis of ADHD,

the most recent research supports ADHD symptoms as a separate construct from ASD

(American Psychiatric Association, 2013). Hartley and Sikora (2009) found that children with

ASD and comorbid ADHD presented with greater impairments in nonverbal behavior, friendship

developments, and imaginative play in comparison to children with ADHD alone.

In addition to comorbid psychiatric conditions, individuals with ASD also have higher

rates of medical conditions. The most common medical diagnosis diagnosed in conjunction with

ASD is epilepsy (Tuchman & Rapin, 2002). As many as 40% of children with ASD are

diagnosed with epilepsy, whereas only 1% of the typically developing population are diagnosed

with epilepsy (Caniato, 2007). Interestingly enough, prevalence rates of anxiety in the epileptic

population are nearly double the prevalence rates of the typically developing population

(Grandy, Sharpe, & Perry, 2013). Another common comorbid medical diagnosis is

gastrointestinal disorders, such as reflux (Horvath & Perman, 2002).

Anxiety Disorders

Typical manifestations of anxiety. Anxiety is defined as a "mood state characterized by

strong negative emotion and bodily symptoms of tension in which an individual apprehensively

anticipates future danger or misfortune" (Barlow, 2002; p. 212). Based on this definition, in

order for a child or adolescent to meet criteria for an anxiety diagnosis, they must experience

excessive anxiety symptoms and those anxiety symptoms must cause significant impairment in a

variety of areas in day-to-day life. It has been well established that anxiety is the results of the

activation of the flight/fight response (Ollendick, King, & Frary, 1989). This response serves the

purpose of preparing the body to escape harm either by "fighting" the source of danger or by

engaging in tactics to "flight" away the source of danger. In general, anxiety disorders can be

broken into three different components: physical, cognitive, and behavioral (Mash, 2003).

When an individual anticipates danger or harm, activation of the sympathetic nervous system has a variety effects on the body including: chemical, cardiovascular, respiratory, and many other physical effects (Barlow, 2002). Chemical effects include adrenaline and noradrenaline being released from the adrenal glands. Cardiovascular effects include an increased heart rate as the body prepares to move the body quickly by increasing blood flow. Respiratory effects include increased speed and depth of breathing in order to increase oxygen intake. Other effects include changes in digestive system (decreased digestion), nausea, trembling, muscle tension and an increase sweat in order to keep the body temperature cool.

When the flight/fight response is activated the mind is primed to immediately assess for the possibility of a threat. As a result, the children and adolescents experiencing anxiety often report difficulties with concentration and focus, because their minds are engaged in threat analysis (Vasey & MacLeod, 2001). It is also theorized that when an outside threat cannot be found, individuals begin to engage in thoughts that either distort the situation to confirm the presence of threat, or even turn the blame for the danger on themselves. For example, in a situation wherein a child cannot identify an external threat they may think "something must be wrong with me" in an attempt to explain their discomfort (Muris & Field, 2008).

The flight/fight response can also prompt strong behavioral responses as children and adolescents experience powerful urges, such as avoidance and/or aggression (Ollendick, King, & Frary, 1989). Common behavioral symptoms associated with anxiety include: fidgetiness, irritability, or complete and/or attempted avoidance of the feared situation (American Psychiatric Association, 2013). Unfortunately, avoidant behaviors are reinforced by the reduction of the anxious symptoms a person experiences when they are able to avoid the feared situation without actually removing the anxiety-provoking stimulus or future fears of it (Muris, & Field, 2008)

Prevalence. Epidemiological studies indicate that between 5.7% and 17.7% of children suffer from an anxiety disorder (Merikangas & Avenevoli, 2002). These disorders often persist over a long period of time. Separation anxiety disorder, social anxiety, simple phobia, generalized anxiety disorder, obsessive-compulsive disorder and panic disorder are the most common occurring anxiety disorders in youth populations (DSM-IV-TR; APA, 2000). It is possible to meet criteria for more than one anxiety disorder, and many of the previously mentioned disorders have overlapping symptoms.

Assessment of anxiety in the typically developing population. Ascertaining if the symptoms are a product of a mild and temporary anxiety or a clinical disorder requires a formal assessment. A basic guideline for separating temporary anxious symptoms from clinical severity is to determine if the presenting fears are reasonable within their context, whether the child responds to suggestions for relieving the symptoms or if the presenting symptoms decrease over time (Chansky, 2004).

Best practice for the diagnosis of anxiety in children involves the use of multiple measures. This can include rating scales, observational schedules, and semi-structured interviews (Morris & March, 2004). The results of assessments are considered to be most valid when information about the child's symptoms is taken from multiple sources including parent, teacher, self-report, and behavioral observation (Morris & March, 2004). It is important to note, however, that interpretation of multiple ratings from multiple sources often show poor agreement among raters; many informants are not aware of the level of symptoms the child may be experiencing (Silverman & Ollendick, 2005). It is the nature of internalizing disorders - such as anxiety - to often show a large level of discrepancy, so care must be taken to ensure the reliability of each response (Silverman & Ollendick, 2005). Rating scales are generally used to

objectively screen for anxiety symptoms and if a child should meet the clinical cutoff then further testing, such as clinical interviews should be used as a follow-up in order to form a more complete diagnostic picture.

Treatment of anxiety. Chorpita, Bernstein, & Daleiden (2011) reported over 100 evidence-based treatments for anxiety disorders in children and adolescents. Despite the wide variety of treatment protocols, there were seven common components found to be shared among cognitive-behavioral based treatments (CBT): psychoeducation, exposure, cognitive restructuring, parenting training, relaxation, modeling and self-monitoring (Rotheram-Boru, Swendeman, & Chorpita 2012). The individual components identified by this study are discussed in greater detail below.

Psychoeducation is an important component to CBT and is typically completed at the start of a treatment. Its purpose is to provide a rationale for the treatment model, with the hopes of gaining "buy-in" from the patient and/or the patient's parents. How behaviors, thoughts and feelings interact are typically discussed at this point and the maintaining factors such as avoidance are also introduced. Exposure is another key technique used in the treatment of anxiety. One exposure technique, systematic desensitization, usually involves relaxation training, arranging anxiety provoking situations in order of intensity, and the pairing of the situations with relaxation training. By pairing the anxiety provoking situations with the relaxation it is assumed that the anxiety will be inhibited via the reciprocal inhibition principle. The goal of exposure is for the individual to experience heightened stress and that by repeatedly exposing the child to the anxious provoking stimuli, the capacity for the stimuli to elicit a feared response will reduce via extinction (Barlow, 2002).

Anxiety presentation in the typically developing population. Anxiety disorders may represent the most common childhood and adolescent disorder, which is concerning considering the significant negative consequences commonly associated with anxiety (Cartwright-Hatton, McNicol, & Doubleday, 2006). The negative consequences associated with anxiety include: lower academic achievement, underemployment, higher rates of substance abuse, and increased risk of comorbidity with other psychiatric conditions (Velting, Setzer, & Albano, 2004). DuPont et al. (1996) estimated that in the year 1990 anxiety disorders accounted for over 30% of the total expenditures for mental illness. Given the cost associated with anxiety, it is reasonable to argue that easily accessible assessment and treatment of anxiety is critical.

ASD traits in typically developing, anxious children. It is important to note that a recent study (van Steensel, Bogels, &Wood, 2013) examined the presence of ASD traits in typically developing anxious children. Using the ADI-R, as well as the Screen for Child Anxiety Related Disorder, 71 (SCARED-71) these researchers compared the presence of ASD symptoms across three groups: ASD, typically developing and clinically anxious. Their results indicated that children with anxiety disorders had significantly higher total scores on the ADI-R and higher scores on all ADI-R domains when compared to the non-anxious typically developing group. Parents of children with anxiety disorders most commonly endorsed items regarding spontaneous imitation, imaginative play with peers, offering to play and imaginative play. Based on their results, clinically anxious children tend to present with more ASD symptoms when compared to their non-anxious typically developing peers. This diagnostic overlap likely adds to the confusion when determining differential diagnoses.

Anxiety in the ASD Population

Although the hallmark impairment of ASD is considered to be overall poor social-communication skills, among adolescents and school-aged children with ASD, as previously

mentioned, anxiety-related concerns are among the most common comorbid presenting problems (Ghaziuddin, 2002). Additionally, while anxiety is not a diagnostic characteristic of ASD, when it is considered a separate disorder, it is recognized that such symptoms serve to further exacerbate the social impairment seen in individuals with ASD (Myles, Barnhill, Hagiwara, Griswold, & Simpson 2001). Research in youth populations with ASD found that up to 84% experienced significant impairment due to anxious symptoms although conservative estimates seem to be settling around 40-50% (White, et al., 2009). In general, children and adolescents with ASD show an increased risk for developing an anxiety disorder in comparison to both their typically developing peers and even developing infants and toddlers not diagnosed with ASD or PDD-NOS (Maston, Hess, & Boisjoli, 2010). Interestingly, Niditch, Varela, Kamps, and Hill (2012) found that higher cognitive functioning in the ASD population was also associated with higher levels of anxiety.

For individuals with high functioning forms of ASD, there is a degree of diagnostic uncertainty when diagnosing anxiety due to the overlap of symptoms between the criteria for ASD and anxiety disorders (Luteijn et al., 2000). The diagnostic criteria for anxiety disorders may include: rigid routines, social withdrawal, and preoccupations with certain topics, all symptoms commonly associated with ASD. Such diagnostic criteria have proven to be less effective for differentiating the diagnosis of ASD from anxiety. The two areas of overlap that make differentiating anxiety from ASD particularly challenging are: social avoidance and compulsive and ritualistic behavior. Additionally, there seems to be a tendency among clinicians to attribute any anxiety symptoms to the core diagnostic features of autism, or as being less significant than the effect of the condition (Lainhart, 1999). Social and emotional reciprocity deficits were also found to be unequally unhelpful in distinguishing between anxious youth and

ASD; this may be due to the presence of reduced social reciprocity in youth with a severely

anxious presentation (Harley & Sikora, 2009). Symptom overlap for specific anxiety disorders is

discussed in greater detail below.

A recent study found that the communication domain best set apart the ASD group from

anxiety disorders (Hartley & Sikora, 2009). However, Davis et al. (2011) noted that as

communication deficits decreased, the level of anxiety decreased in individuals with ASD. The

opposite was found for individuals diagnosed with PDD-NOS. To explain this result they

offered the following hypothesis: as communication deficits increased, it further impaired a

child's ability to verbally communicate any symptoms of anxiety. Niditch et al. (2012) may also

support this hypothesis in that higher cognitive functioning in the ASD population was linked to

higher levels of anxiety. Kerns and Kendall (2012) concluded that anxiety disorders do co-occur

in individuals with ASD. However, they noted that symptoms of anxiety are likely atypical or

distinct in this population when compared to the typically developing population. Kerns et al.

(2014) performed a study to assess for a consistent versus an inconsistent presentation of anxiety

in children ages of 7 to 17 years with ASD by administering questionnaires and semi-structured

interviews to the parents and the child with ASD. Their results indicated that children with ASD

present with both typical and atypical symptoms of anxiety. They concluded that presentation of

the atypical symptoms may be due to the interaction between anxiety and ASD-related traits and

that the presence of typical anxious symptoms highlights the presence of a comorbid diagnosis.

They also reported significant limitations regarding the results of their study noting that the use

of quantitative measures that have not been validated for the ASD population may not accurately

capture and measure anxious symptoms in that population. Renno and Wood (2013) supported

this conclusion when they used structural equation modeling in order to assess for statistical

discrimination between ASD severity and anxiety and their results found anxiety and ASD to be independent constructs.

One example of the atypical anxiety presentation in autism are the inconclusive results that have been found when researching how individuals with ASD manifest psychophysiological symptoms of anxiety in comparison to other controls. For example, one study reported that adults with ASD had lower skin conductance responses when presented with tasks of judging emotions in faces (Hubert et al., 2009). However, another study found increased skin conductance responses in adults with ASD who were performing a face-processing task to compare averted and direct gazes (Joseph, Ehrman, McNally, & Keehn, 2008). Bellini (2006) found that physiological hyper-arousal combined with social skills deficits, could predict social anxiety in ASD.

Research into how anxiety impacts emotional and social functioning and cognition has also been conducted. One study found that when a group of individuals on the autism spectrum were compared with their same-aged, typically developing peers increased anxiety scores were associated with increased risk taking for individuals in the ASD group; the opposite was found for individuals in the typically developing group (South, Dana, White & Crowley, 2011). From these results it was hypothesized that increased anxiety in ASD leads to increased motivation due to a fear of failure. The researchers did note some specific limitations to their study including the lack of validation for the anxiety assessment measure used with the autistic population. Research has demonstrated that anxiety may increase the degree of social impairment and have a substantial negative impact on a person's ability to engage in activities in the home, at school or in general community activities (White, et al., 2012). However, the exact relationship between the social deficits present in ASD and anxiety is not well understood. One study did report that

increased social anxiety symptoms were associated with higher levels of aggression, although a comparative study of rates of aggression in the non-ASD, clinically anxious children was not available (Pugliese et al., 2013).

Solomon and colleagues (Solomon et al., 2008) have reported a significant correlation between increased anxiety scores related to anticipating changes on the Behavior Assessment Scale for Children – Parent Rating Scale (BASC-PRS). Specifically, they found increased levels of loose associations and illogical thinking in ASD children and adolescents (Solomon et al., 2008). Farrugia and Hudson (2006) compared a group of adolescents with Asperger's Syndrome to a group of typically developing adolescents with anxiety disorders. They found that while each group had similar anxiety levels, the Asperger's group presented with significantly higher levels of global life interference.

It is also important to note that there appears to be a disagreement between parent report and youth self-report of how anxiety is expressed and experienced in the ASD population. For example, parents report anxiety as most often relating to the initiation of interaction with peers. Children, on the other hand, endorsed anxiety symptoms that were not related to the parent-reported social impairments (White et al., 2009). Van Steensel, Bogels and Dirksen (2012) reported similar results when the children in their ASD group reported lower anxiety scores than what their parents reported them to have on several scales of the Anxiety Disorder Interview Schedule. This is not too surprising as youth with ASD tend to limited insight and may have difficulty recognizing their feelings and behaviors as symptoms of anxiety. Furthermore, many individuals with ASD have trouble reporting on their anxious symptoms due to the presence of comprehension and/or communication deficits (Gillot & Stranden, 2007). In summary, recognizing anxiety in those with autism is more difficult due to diagnostic overlap, atypical

presentation of anxious symptoms, and the tendency to attribute anxious symptoms to the disorder and not as separate comorbid disorders. Given the atypical presentation of anxiety in this population, it has been suggested that our current anxiety assessment measures, which were normed on the typically developing population, are not an appropriate assessment tools for this specific population.

Specific Anxiety Disorders & Autism

   Obsessive-compulsive disorder and autism. Some research has been done to provide more accurate differential diagnoses between autism and specific anxiety disorders. Obsessive Compulsive Disorder (OCD) is one anxiety disorder that has received significant attention. OCD is characterized by obsessions and compulsions that take up a significant amount of time in a person's day (American Psychiatric Association, 2013). Obsessions are defined as reoccurring thoughts, images, or urges that enter a person's mind and cause significant distress (Rahman, Reid, Parks, McKay & Storch 2011). Obsessions can manifest in a variety of ways, such as fears about cleanliness, or excessive concerns about numbers. Compulsions are the overt behavior associated with an obsessive thought, that are done with the purpose of relieving the distress associated with the obsessive thought or image (Rahman, et al., 2011). Compulsions can be manifested in many ways, such as asking for reassurance or engaging in rituals (e.g., counting, hand-washing, etc.).

   In ASD, restricted and repetitive behaviors and interests (RRBI) are a core diagnostic feature. Given that repetitive behaviors, obsessions and compulsions are core diagnostic features in ASD and OCD, respectively, how to determine if a behavior is a symptom of RRBI versus an obsession or a compulsion, has been a matter subject to much debate. Turner-Brown, Lam, Holtzcla, Dichter, & Bodfish (2011) suggested that the difference between an obsession and an RRBI is the feelings associated with each. Obsessive thoughts associated with OCD cause the

afflicted individual significant distress and compulsions may be used as a way to reduce the distress. In comparison, when a person on the autism spectrum experiences repetitive thoughts associated with RRBIs, the thoughts are not typically distressing, but stopping the thoughts can trigger distress. For this reason, they argue that investigating the purpose of the repetitive behavior may be the key to differentiating the diagnosis.

It is estimated that up to 37% of children and adolescents with ASD have also been diagnosed with comorbid OCD (Leyfer et al., 2006). Lewin, Wood, Gunderson, Murphy, & Storch (2011) have linked a comorbid OCD diagnosis to increased psychosocial impairment. This highlights the importance of accurate assessment in order to provide more targeted treatment. Fortunately the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) was found have good internal consistency, and treatment sensitivity in children and adolescents with ASD, although there was better agreement between clinicians on compulsions in comparison to obsessions, and continued validation of the measure is still needed (Wu et al., 2013). Treatment for OCD in ASD has not received significant attention, but cognitive-behavioral therapy (CBT) is recognized as being the best treatment for repetitive behaviors associated with both OCD and ASD (White et al., 2010).

Social anxiety disorder and autism. Another anxiety disorder with significant research regarding its relationship to ASD is Social Anxiety Disorder (SAD). SAD is characterized by marked fear of social situations, especially those situations that may result in attention and/or scrutiny by others (American Psychiatric Association, 2013). Due to the overlap between symptoms of ASD and SAD, differential diagnosis is sometimes challenging. Both children with ASD and SAD have been found to present with significantly decreased social skills based on parent, and self-report measures (Spence, 1998). Research suggests that the best way to

differentiate SAD social deficits from ASD social deficits is by assessing the onset of the deficit. For children with ASD, the social skills deficits are a core feature, and should present early on in the child's life (White & Schry, 2011). In contrast, it is assumed that the social skill deficits seen in children with SAD are the result of social avoidance and lack of opportunity, and as such the onset of the deficits should begin after the onset of the disorder.

The exact prevalence rate of comorbid SAD in the autistic population is unclear. Community-based samples suggest that it may be as high as 29.2% in adolescents, but lack of validated measures frustrates the diagnostic process (Simonoff et al., 2008). It is likely, however, that adolescents with high functioning ASD are at greater risk for the development of SAD; increased awareness and/or insight into their social difficulties are thought to be a possible explanation for this relationship between SAD and ASD (Kuusikko et al., 2008). Williamson et al. (2008) found that adolescents with high functioning ASD were just as likely to emphasize peer approval as their typically developing peers. These high-functioning ASD adolescents also rated themselves as having decreased social competence. Unfortunately, no specific measures have been developed to help identify comorbid symptoms of SAD in the ASD population. Differentiation in this case relies heavily on clinical judgment to identify the nature of the social deficits and assess for social awareness.

Generalized anxiety disorder and autism. Generalized anxiety disorder (GAD) describes individuals who have trouble controlling their worries. These are children and adolescents who struggle to relax and/or concentrate and although they may realize that their anxiety is too intense for the situation, they can't seem to rid themselves of the thoughts. Physiological symptoms such as headache, muscle tension, and trembling are also common. Some of the symptoms associated with GAD are similar to symptoms of ASD. For example,

strict adherence to schedules or rituals could be attributed to the ASD symptom, need for sameness or it could be attributed to a fear of change, which is better explained by GAD (Gotham et al. 2013).

While an exact comorbid rate has not been determined, Vasa et al. (2013) did find that adolescents and school age children were more likely to have higher rates of GAD in comparison to preschool children. Interestingly enough, Bitsika, Sharpley, Sweeney, and McFarlane (2014) found that parents tended to rate the child's anxiety higher than the child did. When assessing for GAD, they argued that this highlights the importance of using multiple informants when completing a diagnostic assessment. They further noted that it is difficult to assess the rates of GAD given the overlap of symptoms and the lack of measures adapted for the autistic population.

Specific phobia and autism. Finally, specific phobia is another anxiety disorder that has received some attention for how it manifests in ASD. Specific phobic requires that a person's fear be stimulus specific, exposure to that stimulus causes a significant fear response and that the fear response to the stimulus is irrational or excessive. Differentiating core ASD symptoms from specific phobia has proven to be more challenging that expected. For example, it has been well established that children with ASD are hypersensitive to sounds, the question then becomes: when is this hypersensitivity to sound actually a specific phobia? Generally, children and adolescents with ASD have been identified as having more fear when they are compared to their typically developing peers (Matson & Love, 1990). When parents of children with ASD were asked to complete a fear questionnaire, the most commonly reported phobias were: injections/blood draws, making mistakes, getting teeth cleaned, taking tests, meeting peers, doctors, the dark and insects (Turn & Romanczyk, 2012).

One study found that upwards of 44% of children and adolescents with ASD had a comorbid diagnosis of specific phobia using a modified version of the Kiddie Schedule for Affective Disorders and Schizophrenia (Leyfer et al., 2006). Despite this estimate, the researchers noted the diagnostic tool as a limitation, given that the modified version has not been validated with the autistic population. Due to the lack of validated measures for assessing specific phobia in anxiety, the current 'gold-standard' approach suggests a multi-modal (e.g., questionnaires, observation, etc.) and multi-informant (e.g., parent, teacher, self-report) assessment in order to best determine if a comorbid diagnosis of specific phobia is present.

Assessment of anxiety in the ASD population. There are no commercially available measures of anxiety developed specifically for the ASD population. As a result, measures developed to assess the typically developing population are the same measures used to assess anxiety symptoms in those with ASD. As the presentation of anxiety in the typically developing population does not appear to be consistent with the presentation of anxiety in the ASD population, such measures may not be appropriate or valid to use. It would be inappropriate to assume a measure's reliability and validity statistics are the same for ASD individuals.

To address the lack of appropriate diagnostic tools, some effort has been made either to validate current assessment measures for the autism population or adapt current measures to fit this population. A systematic review of the various tools used in studies evaluating the anxiety presentation for high-functioning autism revealed that little to no evidence had been provided to validate measures in the autistic population (Wigham & McConachie, 2014). Renno and Wood (2013) described the limitations in anxiety research when they stated the following regarding their own research:

"It is also important to note that this study used anxiety measures and an anxiety classification system that were originally developed using general clinical samples as well as random population samples, and were not designed specifically for people with ASD . . . our use of the DSM-IV-TR framework for anxiety disorders presupposed in some ways that anxiety symptoms manifestation in the population of people with ASD could be comparable to the typically developing population." (p. 2144)

White et. al., (2014) suggested that determining the degree to which the "construct of anxiety and the psychometric properties of measures used to assess it show equivalence across youth with ASD and those without" would be one process by used to validate anxiety measures in the ASD population. In line with this thinking, these researchers evaluated the properties of the Multidimensional Anxiety Scale for Children (MASC) with an ASD population. Specifically, they compared a sample of ASD youth response to a gender-matched sample of typically developing youth. Unfortunately, neither group sample conformed to the established MASC structure, eliminating the possibility of between group comparisons. What they did conclude was that same latent factors emerged in the ASD group as the clinically anxious group, suggesting that the ASD group has a similar structure of subscales.

Cholemkery, Kitzerow, Rohrmann, S., and Freitag, C. (2013) assessed the ability of the SRS to discriminate between ASD, social phobia and selective mutism. The SRS was shown to have a sensitivity of .83 and specificity of .74 for differentiating between ASD and selective mutism; a sensitivity of .80 and specificity of .84 for differentiating between ASD and social phobia was also found. While the researchers noted that these statistics are acceptable, they are on the lower end. As such they suggested that caution should be exercised when interpreting SRS results. The authors also noted that children with mood or anxiety disorders have also

obtained significant scores on the SRS. This highlights the diagnostic overlap between anxiety and ASD even when using measures designed to assess for autism.

Minimal research has attempted to modify current measures to best fit the ASD population. For example, the Autism Co-Morbidity Interview-Present and Lifetime Version (ACL-PL) was modified in an effort to better diagnose anxiety in the ASD population. The modified version of this measure was only able to endorse the diagnosis of Specific Phobia and OCD in ASD children (Reaven, 2009). Despite recent modifications of different anxiety measures, they are still insufficient for recognizing the presence and degree of anxious symptoms in the ASD population.

Summary

In the above section, literature related to the symptoms and diagnosis of autism and anxiety, and the co-occurrence of anxiety and autism, were explored. The review of the literature suggests that there is some confusion as how to differentiate core autistic symptoms from anxious symptoms. Additionally, current anxiety measures fail to capture the anxious presentation in this population. This qualitative study was designed to gather rich descriptions of how mothers perceive their child's anxiety. The goal of such descriptions was to be able to better characterize the day-to-day presentation of anxiety in the high-functioning ASD population.

<div align="center">

Methodology

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Rationale for a Qualitative Research Model

A qualitative research design was considered to be the most appropriate methodological approach for several reasons. First, when the nature of the research requires exploration, qualitative research is considered to be the method of choice (Stake, 1995). The goal of this research study meets this criteria as it did not test a hypothesis, but rather attempted to garner an

in-depth understanding of what the day-to-day presentation of anxiety in the high-functioning autistic sample looks like. Second, Patton (2002) suggested that a qualitative research method should be chosen when the research questions involve "how" or what." The research questions for this study all involved "what" questions: (a) *What* themes emerge in mothers' descriptions of a child/adolescent's: emotions, actions, physiological arousal, and thoughts for a specific anxiety symptoms or situation?; (b) *What* do mothers attribute as the source of their child's anxiety?; and (c) To *what* degree and in what way do anxiety symptoms interfere with the child's/adolescent's life and family life?; and (d) What methods do mothers observe their children using to cope with their anxiety? Third, Denzin and Lincoln (2000) identified qualitative methods as the most appropriate methodology when there is a desire to understand observable and specific manifestations in a more naturalistic setting and with greater detail. As this study focused on mothers' observations of their child's anxious behavior and their experiences dealing with this phenomenon on a daily basis, a qualitative method was most appropriate.

Thematic Analysis Methodology

Thematic analysis (TA) is a method for analyzing qualitative data that involves "systematically identifying, organizing and offering insight into patters of meaning across a data set. Through focusing on meaning across a data set, TA allows for the research to see and make sense of collective or shared meaning and experiences" (Braun & Clark , 2006; p. 57). Thematic analysis attempts to differentiate between themes that are common versus themes that are meaningful by helping the researcher identify those themes that answer the specific research questions.

Braun and Clark (2006) explained this idea of finding meaning by providing the following example: "For instance, in researching white collar workers' experiences of sociality at work, a researcher may interview people about their work environment and

start with questions about their typical work day. If most or all reported that they started work at around 9:00 AM, this would be a pattern in the data, but it would not necessarily be a meaningful or important one. If many reported that they aimed to arrive at work earlier than needed so that they could chat with colleagues, this would be an meaningful pattern." (p. 57)

Braun and Clark (2006) outlined a six-phase process for completing thematic analysis. These six phases are as follows: "(1) Familiarizing yourself with data, (2) Generating initial code, (3) Searching for themes, (4) Reviewing potential themes, (5) Defining and naming themes, and (6) Producing the report" (pp. 60-69).

Phase 1 (i.e., familiarizing yourself with the data), involves the researchers getting to know the data. This can be accomplished a multitude of ways, such as listening to interviews, reading transcribed interviews, taking notes or watching video data. Phase 2 (i.e., generating initial codes) involves the first process of identifying data that is relevant to the research question. The data that appears relevant is labeled with a brief synopsis and grouped for future analysis. After the codes are identified, Phase 3 (i.e., searching for themes) can begin. During phase 3 codes are grouped together based on their pattern, and patterns are studied to discern a common theme. In Phase 4 (i.e., reviewing potential themes) quality checks are performed in order to assess if the identified codes and extrapolated themes are good fit for the data set. Themes are assessed by their usefulness and coherence in this stage. In Phase 5, (i.e, defining and naming themes), each theme is summed into a few sentences. Braun and Clark (2006) noted that good themes "(a) do not try to do too much, as themes should ideally have singular focus; (b) are related but do not overlap, so they are not repetitive . . . and (c) directly addressed your research question" (p. 66) . In the final phase of thematic analysis (i.e., producing the report),

the research is organized into a cohesive report. It should be noted that Braun and Clark (2006) do not directly discuss saturation as part of TA. Generally, speaking, saturation is considered met when no new themes emerge with additional interviews (Francis, et al., 2010).

Target Population and Participant Selection

Criterion-sampling procedures were used for this study. As this research study was attempting to investigate phenomena that occur within a specific group (e.g., anxiety presentation in high-functioning autistic children and adolescents), criterion-sampling was considered to be an appropriate sampling procedure. Criterion-sampling serves to support the validity of the qualitative data as the sample is able to answer questions about the phenomenon (Creswell, 2007). In this research study, the sample selected met the following criterion: (a) participants were mothers of male children and adolescents diagnosed with an autism spectrum disorder, (b) they were the primary care taker of their child, (c) their sons were between the age of 11 and 16, and (d) their sons were performing course work at their expected grade level and did not have a classification and/or diagnosis of intellectual disability, borderline intellectual functioning or developmental delay. It should be noted that due to recognized gender differences in the presentation of autism symptoms only mothers of male children with autism were included in this study (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2014). Although it is important to understand the impact of anxiety in females with ASD, in order to gather a more cohesive sample only male children were considered for participation.

The sample size involved 20 participants. Participants were recruited by contacting mothers of children and adolescents on the autism spectrum who had previously participated in research through Dr. Mikle South's autism lab or who had participated in social skills groups that he had supervised. All of the participants that were contacted to participate had indicated that they would be interested in being contacted for further research through either previous

participation in the research lab or participation in social skills groups. The majority of the children and adolescents (15 of 20) had previously had their diagnosis of autism confirmed by the administration of the Autism Diagnostic Observation Schedule (ADOS) as part of their participation in previous research studies through Dr. Mikle South's lab. The other five participants had their children participate in the social skills groups through the BYU Comprehensive Clinic. Mothers of children who participated in the social skills groups verbally confirmed that a qualified professional in the community had diagnosed their children with ASD and reported that their child had a long-standing diagnosis of ASD. The Social Responsiveness Scale, a measure designed to assess for social impairment in the autistic population, was given to all participating mothers in order to assess for clinically significant symptoms of autism in their children. The Social Responsiveness Scale, a measure designed to assess for social impairment in the autistic population, was given to all participating mothers in order to confirm the presence of significant autistic symptoms in their children.

Instruments

Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000). The ADOS is a semi-structured and standardized measure of play, communication, imaginative use of materials and social interaction. There are five different modules developed to assess for autism. Modules are chosen based on the child's age and communication level. The ADOS has been found to have good interrater reliability, internal consistency and test-retest reliability (Lord et al., 2000). Additionally, this measure has been found to have good validity for diagnostically separating children with autism from children with nonspectrum disorders. As the majority of the participants were recruited from Dr. Mikle South's research lab, ADOS results were available for 15 of the 20 children of the participants, all using either Module 3 or 4.

Social Responsiveness Scale (SRS; Constantino, 2004). The SRS is a 65 item-questionnaire that contains items that measure a child's ability to engage in reciprocal social interactions and emotional appropriate responses. The social skills this scale measures are believed to be one of the core domains of deficiency in pervasive developmental disorders. Besides reciprocal social behaviors, the SRS also has items that measure communicative deficits, restricted/stereotypic behavior, and the degree to which these behaviors impair normal social behaviors. Using the SRS, items can separated into four social categories that ascertain social awareness, social information processing, capacity for reciprocal social responses, and social anxiety/avoidance. Items are rated on a 4-point severity scale with items ranging from 0 (never true) to 3 (almost always true). Internal consistency for the SRS Total score ranged from .93 to .97on the normative and clinical sample respectively. For the individual subscales, internal consistency ranged from .77 (*Social Awareness)* to .90 (*Autistic Mannerisms)*. This measure was used to confirm the presence of significant symptoms of autism in the sample.

Spence Children's Anxiety Scale, Parent Report (SCAS; Spence, 1998). The SCAS was used to assess the level of anxiety in the individuals participating in the study. This behavior rating scale was designed to be more sensitive to anxiety symptoms in children in comparison to previous behavior rating scales. This measure contains 44 questions rated on a scale of 0 (*never)* to 3 (*always)*. These rating are summed to give a total score, with high scores reflecting increased anxiety symptoms. The 38 anxiety items reflect six different subscales of anxiety: obsessive-compulsive problem, separation anxiety, social phobia, panic/agoraphobia, generalized/overanxious, and fears of physical injuries. There are also six positively worded filler items that are not included in the scoring process. The scale has both a parent and child version in which raters are asked to rate the items on a 4-point frequency scale.

Spence et al. (2003) completed a confirmatory factor analysis of the SCAS to determine whether the measure reflected the six hypothesized dimensions of anxiety disorders. The results of this study indicated that all the items loaded on their hypothesized dimensions at a significant level (Spence et al., 2003). This same study also concluded that the SCAS had an overall high internal consistency (.92) and reasonable level of internal consistency between the subscales: .80 (panic-agoraphobia); .71 (separation anxiety); .72 (social phobia); .60 (physical injury fears); .75 (obsessive-compulsive) and .77 (generalized anxiety). This assessment measure was used in order to assess anxiety in this population. Currently, the SCAS parent report has not been validated for the ASD population.

SCAS parent interview. This interview was developed and used by Dr. Jacqui Rodgers and her graduate student Ruth Jamieson at Newcastle University (Please see Appendix B for a copy of the interview). The questions are designed to expound upon a parent's responses to the Spence Children's Anxiety Scale. It was mainly designed to assess a child's presentation via parent observations, but also included an assessment of how the anxiety presentation impacted both the individual and the family. The structured interview includes up to 32 questions, and depending on parent response it may take approximately 90-120 minutes to complete.

The various questions in this measure were designed to assess the emotional, physical, behavioral, and cognitive presentation of what the mother interpreted to be a manifestation of her child's anxiety. Additional questions inquired as to the degree of interference the symptoms caused, etiology and change over time.

The interview began by asking parents about specific items on the SCAS parent report that they had identified as being a problem for their child. Participants were asked "Can you give me an example of a time when your son/daughter was: [insert specific item here]". After

the participant had identified and provided an appropriate example, then the remainder of the interview questions was administered. Behavioral symptoms were explored by asking open ended questions about the child's behavior during the anxious situation previously identified. Specifically, the participants were asked what it was about their children that made them think their children were anxious and if they observed their children to utilize any coping strategies to manage their distress or attempt to avoid such situations. Physiological symptoms were explored by asking participants whether or not they had observed any physiological arousal in their child, or if their child complained of such symptoms. Asking the participant what they believed their child was thinking about in that type of anxiety-evoking situation assessed for cognitive symptoms. Etiology was assessed by asking when the anxiety response to the specific situation began to emerge and how it how it had changed over time. Interference was also assessed on both a family and individual level.

It should be noted that the interview is edited from its original form. In the original interview, mothers were asked about several pre-determined items from the Spence. These pre-determined Spence items were chosen based on data set that had been collected previously. The data set was made up of a number of Spence forms completed by mothers with children on the autism spectrum that had been completed prior to use of the interview, and the most commonly endorsed Spence from this data set were used as the interview items. For the purposes of this study, the questions were chosen based on participant response to the Spence, and not from a pre-determined set. Items that were endorsed higher on the likert scale (e.g., often and always vs. never and sometimes) were given priority. For example, if a mother marked SCAS item "My child worries that he will do badly in school" as "always" then this item was chosen as a reference point for the interview questions. The questions on the parent interview regarding

emotions, behavior, physiology, etiology, and interference were all asked in relation to the specific situation of the child being afraid to "do badly in school." After all questions were asked in relation to the first SCAS item, a second, third, fourth, fifth, and possibly sixth item from the SCAS was chosen to discuss.

Procedures

Data collection method involved the following: (a) gathering of basic demographic information, (b) completion of two quantitative questionnaires (SCAS and SRS), and (c) administration of a semi-structured interview. Each participant was contacted via phone and provided with a synopsis of the research goals and process. Once a participant expressed interest, a date and time were scheduled for the participant to come to the BYU Comprehensive Clinic for a face-to-face interview with the researcher. Of the 34 participants who were called, 20 agreed to participate in the study. Outlined here is each step of the process: 1. The recording device (a laptop computer with an installed Audacity software recording program) was set on the table in proximity to both the researcher and participant.

2. The researcher reviewed the informed consent with the participant that included a discussion of the purpose of the study, what information would be gathered, how the information would be analyzed and compensation. Ethical guidelines, including the option the participant would have to remove herself from the study in the future if needed were also discussed.

3. After review of the consent form, participants completed an online questionnaire that gathered the basic demographic information, and completed an online administration of the parent versions of the SCAS and SRS.

4. The researcher identified 5 items on the SCAS that the participant identified as most often applying to their child.

5. Once the items were identified the researcher invited the participant to ask any questions about the research objectives or process, prior to the start of interview.

6. The researcher obtained permission from the participant to begin recording the interview portion of the process.

7. The participant completed 5-6 sets of the SCAS Parent Interview using the items taken from the SCAS parent report questionnaire within a 90 to 120 minute time limit. The number of sets that each mother completed was based on how long each set took to complete.

8. After completion of the interview, participants were provided with compensation ($45 VISA or AMAZON gift card) for their participation.

　　　　After the interviews were completed they were transcribed prior to the analysis of the data. All written documents (transcripts, consent forms, and related documents) are kept on either an encrypted USB drive that features HIPPA compliant encryption or in a locked cabinet in a research lab.

Data Analysis

　　　　Data analysis followed the outline of thematic analysis (Braun & Clark, 2006). First this researcher replayed interviews and transcribed them into computer files. All transcribed files were quality checked by the researcher by reading along the transcription with the audio once transcription was complete. If more than 10 meaningful errors were identified (i.e., errors that would change the meaning of a statement), the written data was reviewed a second time. No interviews had more than 6 meaningful errors when they were reviewed. The researcher transcribed the interviews verbatim. No corrections for grammar or interruptions were provided. If a word was difficult to understand, it was transcribed phonetically. It should be noted, that for one interview, the recording device experienced technical difficulties when converting the file to an mp3 format. As result the last 35 minutes of the interview was corrupted and only 60 of the

95 minutes of interview were available for review and transcription. As the majority of the interview was still available, and three items from the SCAS had already been discussed in the first portion of the interview, the available transcribed data was considered to still be useable and a contributing source for the data analysis.

Two coders were recruited to assist in triangulating the data. The coders were undergraduate students obtaining Bachelor degrees in Psychology or Neuroscience at Brigham Young University. Initially, this researcher and the two coders read the transcribed interviews and made notes regarding common themes or data points discussed across interviews. After all the coders had read the interviews independently, several meetings were held to compare impressions and notes. During these meetings, coding procedures were discussed and eight major themes emerged during the initial phase. The interviews were then uploaded into a qualitative research software program called NVIVO. This program allows the readers to create codes based on reader-identified themes. Once a code (called "node" in the program) has been created based on a reader-defined theme, a reader can highlight text directly from a document and label it under a particular code. The program then allows readers to review coded themes by grouping the highlighted codes across interviews.

Initially, readers coded only a selection of interviews in order to assess for intercoder reliability. Intercoder reliability is a term often used to describe the degree of agreement between coders performing content analysis. Although not used universally in qualitative studies, this calculation can be helpful at demonstrating agreement between raters that points to acceptable operational definitions of the identified codes. Each coder was randomly given three interviews to code and reliability across coders was calculated using software ReCal to calculate Fleiss' kappa (Freelon, D., 2010). Fleiss kappa can be used to calculate intercoder agreement

among multiple coders (i.e. more than 2) and for small sample sizes. Fleiss' kappa compares the rate of agreement of readers to the expected rate of agreement. A general guideline for interpreting Fleiss' kappa is as follows: .60 - .74 indicates intermediate to good agreement between coders and .75 or higher indicates excellent agreement. The average Fleiss' Kappa for the three interviews was calculated to be .70, which indicates intermediate to good agreement among coders. For exploratory qualitative research intercoder agreement above .7 is considered adequate (Lombard, Snyder-Duch, & Bracken, 2002). Operational definitions were reviewed and clarified at this phase and coders continued to code the rest of the interviews, with codes being kept based on reader agreement. After all the identified codes were agreed upon and defined by this researcher and two readers, the three readers then coded the interviews using the NVIVO software.

After the interviews were coded, phase 3 began. The codes were reviewed for frequency of occurrence and analyzed for cluster patterns in order to identify themes. The identified cluster patterns of codes and how they related to each other were discussed between this researcher and the two additional readers. A code was considered significant if the majority of the participants reported it. In multiple cases, smaller codes were subsumed into a larger theme. For example, the coping strategies of playing with non-electronic devices and playing with electronic devices when anxious were originally coded separately. However, as the purpose of using the different items was similar in nature, they were grouped into a single theme, "Distraction." Those codes that were not reported by the majority of participants and were unable to be grouped into a larger theme are not reported in the result section. Only four codes were note included in the finalized themes. Codes not included were: sensory issues explained emergence of fears (reported by 4 participants), alone time reduced anxiety (reported by 3 participants), fatigue was a symptom of

anxiety (reported by 4 participants), and having an external reward reduced anxiety (reported 4 participants). Table 1 provides an outline of the final themes identified. In phase 4 the identified cluster patterns of codes and how they related to each other were discussed between this researcher and the two additional readers. Finally, in phase 5 the themes were identified, defined and supporting data (i.e. specific quotes) was grouped with the identified theme. Phase 6 is the presentation of the results portion of this paper.

Validity Criteria

Kazdin defined reliability as the "the extent to which the measures assess the characteristics of interest in a consistent fashion" (2003; p. 581) and validity as "the extent to which the measure assesses the domain of interest" (Kazdin, 2003; p. 583). Measures of reliability and validity are different in qualitative research when compared to quantitative measures. To address the validity of this research, the outline of a validity model for qualitative research, as defined by Whittemore, Chase and Mandle (2001) was consulted. They defined four different types of measures that qualitative research can use to assess for validity. The measures of validity were: design consideration, data generating, analytic and presentation. Within those four types of measures of validity, 29 specific techniques were provided (Whittemore, Chase & Mandle, 2001) This research design used 15 of the suggested techniques and these are outlined as follows.

The first measure of validity is "Design Consideration" (Whittemore, Chase & Mandle, 2001; p. 3). This study utilized the following techniques for validating the design consideration: "developing a self-conscious research design, employing triangulation, giving voice and expressing issues of the oppressed group" (Whittemore, Chase & Mandle, 2001; pg. 3). This research design evidences a self-conscious component, in that personal biases were discussed among the readers and this researcher, as well as with the dissertation chair. Triangulation was

Table 1.

Themes that Emerged from Question Responses

Question/Theme	# of Participants	# of References	Description	Example
In what way does this interfere with family life?				
Family Changes	20	45	Changes in schedule or plans	"We can't just jump in the RV and start driving, we need to have a destination and we need to have some kind of general itinerary just so he can have that comfort level and feel comfortable going with us on the trip" (Participant #2)
Time Demands	19	42	Large and/or daily time commitment to manage anxious symptoms	"It was a 15-minute job turned into an hour and a half" (Participant #3)
Emotional Toll	20	67	Increased stress, frustration, etc.	"It's just so draining when one of your children is just so distressed about things all the time and I think it affects the other children a lot. Just the mood in the house changes" (Participant #4)
In what way does this interfere with your child's life?				
Quality of Life	20	53	Reduction in participation in social, occupational, academic activities	"It limits him for what he is willing to do" (Participant #16)
What was it about what your child did in that situation that made you think that your child was anxious?				
Avoidance	20	79	Any behavior indicating avoidance of a situation	"Grabbing onto me, hiding behind me, and this has been some time ago, like this happen then really recent." (Participant #20)
Changes in Mood and Affect	19	62	Descriptive words such as: crying, screaming, mad, meltdown, etc.	"There's yelling, others often stomping around. A lot of ugly faces. Sometimes yelling. Even if he is not yelling he would say things, "I hate you. You're a terrible parent." You know those kind of things kids say when they're mad" (Participant #1)
Physical Aggression	18	43	Behaviors such as: hitting, kicking, pushing, throwing, etc.	"he will push through and get somewhat physically violent. You know like push you away or he's hit" (Participant #17)

Table 1 continued

Question/Theme	# of Participants	# of References	Description	Example
Did your child do anything to reduce/manage/prevent his distress in this situation?				
Distraction	20	71	Coping strategy that involved using distractors to reduce anxiety	"I guess it depends because sometimes he goes and distracts himself doing other things, go get his Legos out and start building, sort of entertain himself in other ways" (Participant #13)
Be Prepared	20	65	Engagement in any behavior that involved problem-solving/preparing for the anxious situation	"I think he tries to manage it a little bit by taking his binder with him everywhere he goes. . . He thinks that maybe if he has that, he'll be prepared for anything" (Participant #14)
Do you think these feelings brought about any uncomfortable bodily sensations in your child?				
Tension	18	74	Behavioral descriptions of tension	"his muscles were really tight in his face and all over his body too" (Participant #19)
Restlessness	18	56	Behavioral description of restlessness, difficulty relaxing	"gets more fidgety . . . he's stands, he rocks, he spins, he fiddles with things. I've learned to give him things to fiddle with" (Participant #8)
Sympathetic Nervous System Changes	16	18	Descriptions of: increased heart rate, increased breathing, etc.	"racing heart, headache, feeling like he is going to pass out sometimes" (Participant #9)
What thoughts do you think went through your child's mind in that situation?				
Fear of Failure	18	44	Fear of making mistakes or not doing something in just the right way	"What's the worry? Probably just self-doubt or like he doesn't have the confidence enough to know that it's okay if it's not perfect. I think he is just innately a perfectionist in some things" (Participant #12)
Fear of Social Judgment	20	58	Fear of negative judgment by peers	". . .afraid he would look foolish. He didn't want to be the center of attention in class and have everyone looking at him" (Participant #17)
Fear of Uncertainty	19	57	Fear of the unknown	"It's the fear of the unknown, I think, is the mostly what he's worried about . . . He likes to know what's coming, he likes to know what to plan. So it's mostly, I think it's the unexpectedness of it that's the issue for him" (Participant #2)

Table 1 continued

Question/Theme	# of Participants	# of References	Description	Example
Can you pinpoint when this problem began to emerge? What was happening around that time to explain the emergence of the fear?				
Social Difficulties & Awareness	18	51	Social difficulties or increased awareness of social rules explained emergence of anxiety	Fears began "in the 5th grade" because "there was a boy that would bully him in his class" (Participant #7)
Growing Older/Changes	17	42	Changes in routine or responsibilities due to growing older	"he didn't have very much homework [when he was younger]. He didn't have a lot of other activities. I think that it was easier for him to balance. He didn't have any other cleaning responsibilities. I did all that for him. I guess he's getting older and having more responsibilities placed upon him" (Participant 12)
To what extent do you think these thoughts were reasonable given your child's circumstances? What was it about your child's circumstances that made you think his thoughts were reasonable?				
Condition	20	67	Anxious feelings/thoughts reasonable due to ASD	"I think it's reasonable for him because he's got that emotional kind of almost like a disability where he doesn't know how to deal with it" (Participant #4)

employed by involving multiple readers to examine and the data and discuss various interpretations. This research gave voice to mothers of children with autism, about their day-to-day observations and experiences with their child, which quantitative measures cannot fully capture. Finally, it can be argued that although mothers of children with autism are not an oppressed group, they can be considered an underrepresented group, given that they have unique experiences that are not always well understood by the general public.

The second measure of validity is "Data Generation" (Whittemore, Chase & Mandle, 2001; p. 3). This study used the "articulating data collection decisions and providing verbatim transcriptions" (Whittemore, Chase & Mandle, 2001; p. 3) techniques for this measure of validity. Data gathering plans and goals were explicitly discussed and outlined by all parties

involved in the research, and all transcriptions were completed verbatim, and emphasized accuracy.

The third measure of validity technique is "Analytic" (Whittemore, Chase & Mandle, 2001; p. 3). This study utilized the following techniques: "articulating data analysis decisions, using computer programs, data reduction tables, exploring rival explanations, and performing a literature review" (Whittemore, Chase & Mandle, 2001; p. 3). This researcher worked with the two readers in order to discuss how to analyze the data, and why the specific methods were chosen. Additionally, the computer program, NVIVO, was used to in order to improve flexibility and validity. Although data reduction tables were not drawn, codes were organized into major categories and subcategories. This allowed easier identification of less common themes to be removed. Rival explanations for the various codes were discussed, including participant knowledge base and biases, as well as researcher biases. As is evident from the above section, a literature review was performed using the PsychInfo database to search for key terms related to anxiety and autism, which is another important component of satisfying the condition for analytic validity.

The fourth measure of validity is "Presentation" (Whittemore, Chase & Mandle, 2001; p. 3). To address this measure of validity, this study utilized the following techniques: "providing an audit trail, providing evidence to support the interpretation, acknowledging this researcher perspective, and providing descriptions" (Whittemore, Chase & Mandle, 2001; p. 3). The audit trail for this research study includes: all recorded interviews, transcription of interviews, and NVIVO coding notes. This research study also posited that the interviews and codes provided adequate support the interpretations discussed in the following result section. This researcher and readers all acknowledge their biases. This researcher also noted her personal family history

of having a brother on the autism spectrum. Finally, the results sections provide in-depth description of the themes that were identified by this researcher and readers.

Ethical Considerations

When working with an underrepresented population, ethical considerations are considered to be especially important. As this study asked mother to share their thoughts, feelings, and observations of their special needs child, protecting their privacy was of great importance. The American Psychological Association (2002) provided the following elements as some of the key components to ethical research: protection from harm, equity, informed consent, and right to privacy.

This study aimed to protect them by utilizing an informed consent. The informed consent educated the participant regarding the risks involved with the participation, which were minimal, and explained how their privacy would be protected. Their option to have their interviews removed at any point during the course of the study, without the loss of their compensation was discussed. Participants were invited to ask any questions about the research at any time. A copy of the informed consent is in appendix.

<div align="center">

Results

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Description of the Sample

Demographic information of participants. Interviewed participants ranged from 35 to 54 years of age, with an average age of 43 years. All the mothers had male children diagnosed with an autism spectrum condition, and all had other children as well. Sixteen of the mothers described were homemakers, and four had full-time employment outside of the home. All mothers described themselves as religious and reported that they were Christians. All mothers identified their ethnicity as "Caucasian."

Description of Participants' Children

   Demographic information. The average age for the participants' sons was 13 years, with their ages ranging from 11-years to 16-years. Participants also reported if their child had ever been diagnosed with any other psychiatric conditions. Comorbid diagnoses included depression (8 children), anxiety (8 children), ADHD (12 children), learning disorder (3 children), bipolar disorder (3 children), OCD (2 children), Tourette's (1 child) and intermittent explosive disorder (1 child). Two of the participants children were reported to have no comorbid diagnoses. 16 had multiple diagnoses in addition to the Autism diagnosis. None of the participants' children had been identified with an intellectual disability. All were in mainstream classes and completing coursework at their expected grade level, per maternal report. Regarding comorbid medical conditions, 3 of the participants reported that their child had experienced a seizure. Current and past psychotropic medication use was not assessed as part of this study. Current or past participation in therapy to address anxiety was also not assessed.

   ADOS scores. Of the 20 children that were discussed by the participants, 15 had been assessed using the ADOS. The average ADOS score across the 15 participants was 13, with scores ranging from 9 to 20. Based on the ADOS cut-off scores, which were designed using DSM-IV-TR criteria (7 and above indicates ASD), all 15 of the participants' children met criteria for an autism diagnosis. ADOS scores were not available for the other 5 children as they were diagnosed outside of the clinic.

   SRS scores. The SRS uses a T-score cut-off system. A T-score of 76 or above is considered to be in the severe range. The average T-score for the participants' children in this study was 78, which is in the severe range. T-Scores ranged from 56 to greater than 90.

   SCAS scores. The SCAS has not been yet normed with the ASD population. However, current normative data using the typically developing anxious population suggest that the

average parent report score indicating significantly anxious symptoms for this measure is 31 for

boys 6-11 years of age and 30 for boys 12-18 years of age. Parent report of their child's anxiety

on the SCAS ranged from 1 to 87 with an average SCAS score of 32. It was decided that

mothers who did not report clinically significant anxious symptoms in their children via the

SCAS would not be excluded from this study. This is due to validity and diagnostic issues that

are associated with using measures not normed to the autistic population.

Presentation of the Data and Results of the Analysis

   This section presents the analysis to answer the research questions: What themes emerge

in mothers' descriptions of a child/adolescent's: emotions, actions, physiological arousal, and

thoughts for a specific anxiety symptom or situation? What do mothers attribute as being the

source of their child's anxiety? In what way do anxiety symptoms interfere with the

child's/adolescent's life and family life on a day-to-day basis? What methods do mother observe

their children using to cope with their anxiety?

   The themes are not presented in a specific order based on frequency of response. Rather

the themes are organized based on the structure of the questions in the interview. For example,

the themes that emerged when mothers were asked to describe how they recognize their child's

anxious behaviors are grouped together; the themes that emerged when mothers were asked to

identify physiological symptoms, family interference, and individual interference and so on were

grouped in a similar fashion. It should be noted that in order to avoid unnecessary redundancies,

not all the quotes supporting a specific theme theme are discussed. Instead samples of responses

that exemplify the overall themes are provided. Additionally, the themes are not presented in any

specific order based on frequency.

Theme 1: Anxious Symptoms in Children with Autism Negatively Impacts the Whole Family

When mothers were asked if their child's anxious thoughts and behaviors interfered with family life, the overarching theme that emerged from their answers was every participant reported that their child's anxiety negatively impacted the entire family and themselves personally. This theme evolved from coding how mother talked about family interference; changes in what the family can do, significant time demands, and emotional distress are the types of ways anxiety interfered with anxious life.

Family changes. Many of the participants shared their stories about how their family has changed schedules and plans in order to help reduce the child's anxiety. They shared how the family changed the way they traveled, changed where they ate as a family, or even what activities they participated in to help reduce their son's anxious symptoms. Participant 19, for example, described how she isn't able to take her children every place she would like to go, because of her autistic son's anxiety. She describes the following situation:

> "And I took him and he walked around for half an hour and he just started getting anxious and decided that he wanted to go sit in the car and draw... after half hour. I mean [younger brother] would have loved to go to The Living Planet Aquarium, he would have loved it. But, because [Name I] would have just wanted to sit in the car the whole time, we didn't go . . . Because it would have been like pulling the teeth and I would have to bribe him and promised to only stayed for 30 minutes. And that's not worth my time . . . I live in [City A], that's all the way down in [City B] and I'm not going to drive an hour each way so that we can stay there 30 minutes he thinks that the world revolves around him, and it's because sometimes it does" (p. 11)

Participant 9 noted that she has to adapt her schedule and planned events to her child's anxiety. She shared "Have you ever tried to get a babysitter for a fifteen year old? . . . It makes it very challenging to do other things besides be at home" (p. 8). Participant 2 shared the story of her son becoming anxious when they first went on a trip without any plans:

"Yeah, we can't just jump in the RV and start driving, we need to have a destination and we need to have some kind of general itinerary just so they can have that comfort level and feel comfortable going with us on the trip." (p. 30)

Time demands. Mothers also reported that their child's anxiety often demanded a large and sometimes daily time commitment. One mother explained how simple activities, such as completing a homework assignment, could take up much more time than expected, "it's usually all the time. I usually have to prep him in advance. If he has to speak in front of people, we have to do whatever he is talking about. We need to do it over and over in advance" (Interview 18; p. 12). Participant 14 reiterated this idea, when she stated that her son's anxiety could turn a "15-minute job turned into an hour and a half" (p. 43). Participant 3 stated, "We have to do a lot of monitoring for him, and make sure he's not getting – sometimes he's his own full-time job" (p. 24). As Participant 10 stated simply "our family revolves around him" (p. 15).

Emotional toll. The final theme for family interference was the emotional toll that it took on either themselves or on the family. Mothers spoke openly about the stress that was associated with helping to manage what they perceived to be their child's anxiety. Participant 4 described her child's anxiety as, "It is, it's emotionally... It's just so draining when one of your children is just so distressed about things all the time and I think it affects the other children a lot. Just the mood in the house changes" (p. 42). Mothers reported that their child's anxiety could present as anger toward them or towards other family members. Participant 7 noted the impact

that her son's anxiety had on the family, "Just the constant contention constantly everywhere." (p. 34). She goes on to explain,

> "That he feels like there should always be a compromise, so I'm sure he's feeling that it's not fair, - that we're mean, and that - you know, and it's not the normal. Because we usually try to compromise. Do you know what I - do you understand what I'm saying?" (p. 57).

Mothers described how the whole family can be negatively impacted by the child's anxiety, and mothers often felt it was their responsibility to calm the child down and act as the go-between for the child and the rest of the family. This role was described as being emotionally taxing. Participant 5 reported the following:

> "It causes a lot of frustration when trying to get him to comply with behaviors, like getting ready on time, stuff like that. And if he is just so over the top with his feelings about the burglary scenario or somebody breaking in, hurting his house or hurting his family, it's a big deal to him and it's disruptive to the whole family. It's like the girls really get frustrated with it. His dad gets frustrated with it. I get tired of it but then, I have to remind myself, I am the mom and I can't really... you know what I mean? So, I have to try and coax him through this." (p. 8)

Participant 1 noted that she feels as though she has though she also has to explain to people outside the family about her son's anxiety, a sentiment shared by many of the other mothers in this study.

She notes:

> "We have to explain his situation to all the people working with him so that they know what to explain well what they are doing and why they are doing it and how it's going to

feel like those kind of things. I think it probably takes a bit longer than otherwise would." (p. 19)

Theme 2: Anxiety Interferes with the Child's Life

In addition to family interference, the mothers were asked if anxiety significantly impacted their child's life. From their responses emerged the theme that anxiety was a culprit holding their child back from engaging with their peers, enjoying activities, or even accomplishing day-to-day tasks. Participant 16 summed up the impact anxiety had on her child's life with the statement "It limits him for what he is willing to do" (p. 35). This fits with the current model of anxiety which states that in order for an anxiety diagnosis to be clinically significant, it must result in significant impairment in various areas of functioning such as social, occupational, academic etc.

When mothers were asked how anxiety inferred with their child's life, they had a lot to say. All of their stories could be summed up in one general idea: anxiety imposed limits on what their child felt he could do and what he could enjoy doing. Some described how it limited the child in specific areas such as school or social situations. Participant 14, described her child's anxiety by stating, "it's fairly interfering because . . . he can't progress, like he can't – Yeah. It'd block his progress" (p. 44). She went on to describe how his anxiety prevents him from performing well in an academic setting, stating "Because it almost immobilizes him from getting good grades . . . Because it's preventing, he's so concerned about what he hasn't done that he's forgetting to do what he can do about the problem" (p. 68). Participant 5 reported that her son's anxiety prevented him from going to church. She stated, "Even though he wants to go to church, he's afraid to go to church" (p. 8). Participant 8 shared a similar belief as she noted, "there's a lot of things that he doesn't do that his age does. So it holds him back from engaging with his peers,

and going to school" (p. 10). When asked the level at which her son's anxiety interferes with his life she stated:

"I think it's very interfering . . . him not being able to communicate with his peers . . . him not being able to do the activities his peers are doing . . . because if it's overwhelming to him, he'll cry or he'll just shut down and not be able to do it" (p. 15).

Even in social settings where the people involved were familiar, parents still noticed that the child's anxiety could interfere.

Parents often noted that limitations caused by anxiety were especially notable in social settings. Participant 16 reported that due to anxiety her son is "very hesitant to try new things . . . to meet people, anything, any transitions are very hard for him. And new people is very hard for him too" (p. 34). Participant 6 also reported that when participating in social activities her son often demonstrated social deficits due to anxiety. She reported, "He's more hesitant to do things around his own peers that they're going to make fun of him for. He doesn't understand if they're making fun of him or if they're joking with him, he doesn't get that" (p. 36). In this exchange, later during in her interview, she also noted, similar to other mothers, that the anxiety completing prevents her son from participating in various activities:

"Participant 6: It's fairly interfering.

Interviewer: Fairly interfering. In what way is it fairly interfering?

Participant 6: Sometimes he won't go to scouts. Sometimes he won't go out and do things.

Interviewer: So prevents him from once again, socializing?

Participant 6: From interacting in life" (p. 23).

Impairment in social functioning also occurred in family activities, with mothers describing their child's anxiety as impacting family activities and events. Participant 13 reported that her son's anxiety, "prevents him from doing things that he would enjoy doing or even sometimes with the family. So we have to coerce him some or he will not do this or that or other activities" (p. 42). Participant 12 provided a perfect summary of how anxiety impacts her child's life with the statement, "Because he, his anxiety, the anxiety just causes him to not enjoy life" (p. 23).

Theme 3: Mothers Can Identify Anxiety by Their Child's Behavior

Diagnostic criteria for the various anxiety disorders all require specific behavioral symptoms to be present. Some examples of behavioral symptoms of anxiety include avoidance of the feared stimuli, and increased irritability. When mothers were asked what actions and behaviors their child engages in when anxious, every participant was able to describe in detail the various actions their child engaged in and several themes emerged: avoidance, aggression, and changes in mood and affect.

Avoidance. Every mother described times when her child avoided a situation due to anxiety. Participant 11 noted that her child would seem to cope by avoiding. She stated, "Sometimes when he gets stressed, he'll just go lie in bed and put the covers over him" (p. 44). Participant 20 described how her child would avoid situations that involved social interaction by simply refusing to go. She explained this in the following exchange:

"Interviewer: "...expected of you", okay. Does he do anything to avoid this kind of situations or...?

Interviewee: There are sometimes he will choose not to go.

Interviewer: Okay, so he won't just go out to eat?

Interviewee: Yeah." (p. 22)

Similarly, another mother described how her child would avoid getting up in front of the class by simply refusing to participate in the feared activity, even when in the presence of peers. She describes,

> "Um, he, um, in his resource class, they're supposed to get up to the board and answer a question, and he, um, not only wouldn't volunteer, but would, or has refused to go up to the board 'cause he doesn't want to be up in front of everybody. Although they've got him in a small group now and are kind of tweaking things and he's um, getting, I think, more comfortable (Interview 3; p. 14)

Mothers also noted how their child's avoidance could manifest as avoidance of specific tasks as well. Participant 10 noted in the following exchange that her child would engage in procrastination type behavior to avoid a challenging assignment.

> "Interviewer: Okay. What will he do in the situation to avoid it?
>
> Interviewee: He just didn't do the project.
>
> Interviewer: The work.
>
> Interviewee: Yeah.
>
> Interviewer: Okay.
>
> Interviewee: He did everything else but that and he just keep-
>
> Interviewer: Okay.
>
> Interviewee: Being slow on it and stuff" (p. 4)

Mothers also described how when their child wasn't able to avoid the fear stimuli completely, their attempt to engage in avoidant behaviors could become more intense. For example, mothers talked about how sometimes their child would make themselves smaller when they had to face the feared situations. Participant 20 stated the following:

"Interviewer: What exactly was he doing in that situation that made you think why he is anxious?

Interviewee: Grabbing onto me, hiding behind me, and this has been some time ago, like this happen then really recent. He was hiding behind me, grabbing on to me -- he was crying.

Interviewer: Okay.

Interviewee: He would not even go into the room they were practicing" (p. 1-2).

Participants' also described how their child might try to come up with excuses to get out of specific situation. This exchange with Participant 6 highlights this avoidance technique as she describes her child attempting to find excuses to avoid a specific situation.

"Interviewee: He was very straight-faced, showed no emotion, drag his feet, did not want to go in the school.

Interviewer: Okay.

Interviewee: Hid behind me, tried to pull my shirt to hide in it.

Interviewer: Okay.

Interviewee: Quite a few things.

Interviewer: Okay.

Interviewee: I mean, he just-

Interviewer: So thinking about those things that he did, what specifically did he do? Or did he do anything to try to avoid this situation? So, avoid going to school or avoid thinking about the thoughts.

Interviewee: My tummy doesn't feel good.

Interviewer: Okay.

Interviewee: I think I'm sick, mom.

Interviewee: I need to stay home.

Interviewer: Okay.

Interviewee: He did try to get out of them." (p. 3)

Participants also noted that sometimes their son's avoidance could increase in intensity unexpectedly. Participant 15 described the following situation:

"There was a situation, - probably about 6 months ago -, I can't remember all the details

of it but he and I kind of gotten an altercation - teenagers. I told him he couldn't go down

to his room and cool off because I needed him to stay there and focus with me. He

wouldn't stay there and focus, so he bolted. He was gone for several hours. We had to

call the police and whatnot. They found him about 5 miles away.

Interviewer: He just walked?

Interviewee: He just walked. He just... if he can't handle the situation, he just walks."

(p. 3)

Changes in mood and affect. Changes in mood and affect are symptoms criteria for various anxiety disorders. One criterion for generalized anxiety, for example, is the presence of irritability. In the DSM-V it is noted that fear or anxiety in social situations for children with Social Anxiety Disorder, can present as tantrums, crying or clinging. The participants in this study reported that changes in mood and affect cued them into their child's anxiety. The word "crying" or "cried" was used 86 times by participants to describe their child's behavior when anxious; "upset" was used 108 times; "scream,' "screaming" or "scream" was used 48 times, "angry" was used 65 times; "mad" was used 52 times; and "meltdown" was used 43 times by mothers to describe the changes in their child's mood and affect when they were anxious.

In this exchange with Participant 14, she describes a typical example of how she recognizes her child's anxiety by changes in his mood and affect:

"Interviewer: Yeah. What did your child do in the situation? So, what did he do in the situation that made you think, "Hmm, he's anxious."

Interviewee: Well, the crying.

Interviewer: Okay.

Interviewee: He starts crying and raising his voice" (p. 58).

Participant 19 also talked about a typical example of her child's anxious mood and affect. When asked about how she knows her child is anxious, she described how in situations when her son is trying to avoid an anxiety provoking situation, "he continues to argue. . . until I give him a consequence that's severe enough that motivates him to be quiet" (p. 21).

In addition to "crying," "yelling," and "arguing" participants also described increased tantrums when their child was anxious. For example, Participant 12 and Participant 1 both talked about "meltdowns" occurring when their child was anxious. Participant 12 described her child's meltdown as " [he] just cries and just kind of throws a teenage tantrum and just has a major melt down like his life's gonna end and oh my gosh he can't handle this" (p. 18). Participant 1 described her son's meltdowns as

"there's yelling, others often stomping around. A lot of ugly faces. Sometimes yelling. Even if he is not yelling he would say things, "I hate you. You're a terrible parent." You know those kind of things kids say when they're mad" (p. 37).

Participant 5 summed up her child's mood changes with the statement,

"it's just like autistic kids work really hard to keep it together during school and public situations. It's like the gloves come off when they're at home and all you see are the raw,

naked emotions but it's like sometimes you don't even see that, you just   see the nasty

behaviors and so, you have to be like, "Wait a minute, I got to take a step back what's

driving this? Why is he being so impossible?" (p. 11).

Physical aggression. Participants also reported that their child's mood changes can be

accompanied by physically aggressive behaviors. Physically aggressive behaviors included

behaviors such as: hitting, kicking, pushing or throwing items. Of note, when instances of

physical aggression did occur, it was often within the context of the child experiencing extreme

symptoms anxiety and finding himself unable to avoid or escape a feared situation or engage in

preferred coping strategies. When asked what her son's anger looks Participant 20 stated, "he

yells, he throws things, he hits walls, like he can go into a rage" (p. 12). Participant 17 noted that

when her child's anxiety reaches his peak "he will push through and get somewhat physically

violent. You know like push you away or he's hit" (p. 10). Participant 8 also described her son's

aggression in the following exchange:

"Interviewee: He will also throw things.

Interviewer: Like whatever is in his hands?

Interviewee: And he's broke computer by throwing headphones at it. He tried to-- almost

broke the windows on the van from the inside you know." (p. 15)

Mothers also described how their child wasn't always aware of how they could hurt

others. Participant 14 talked about her son doesn't seem to be aware of his size and they have to

be careful when he his anxiety reaches his peak, as he isn't always in control of his physical

behavior. She describes this in the following exchange:

"Interviewee: And, very aggressive and when his aggressive like that, we

can't even approach him…

Interviewer: Okay.

Interviewee: …because he is so big. We could get hurt." (p. 5).

Participant 8 also described how when experiencing high levels of anxiety her child struggles to control is physical responses. She notes "He'll run, he will hit . . . he'll throw things at you. He just explodes and he even describes it that way. He also says it's inside me and it has to get out" (p. 5).

Theme 4: Children with ASD Utilize Distraction and Preparation as Coping Strategies

During the interview, participants were asked if their child engaged in any activities to cope with the anxiety that they experience. Analysis of the qualitative data revealed that two major types of coping strategies were reported: distraction through toys and media or gathering information.

Distraction. Reading, playing with media (e.g., computer, T.V., iPad, etc.) and other toys were the preferred coping strategy that the participants reported as being the most common ways that their children would reduce their anxiety. Participant 1 noted that during an anxiety provoking situation (e.g., taking a plane ride) her son would bring distractors for himself to use in order to help calm his anxiety. She stated "He brought some videogames that he could play while he was on the plane" (p. 24). Participant 13 noted, reported similar observations. When asked what her son did to cope with his anxiety she reported "I guess it depends because sometimes he goes and distracts himself doing other things, go get his Legos out and start building, sort of entertain himself in other ways" (p. 28). Participant 8 reported that her son doesn't always have a particular distractor that he went to, but using some sort of electronic device was helpful. She stated, "he'd often put on some music on his phone and listen to that. The texting or, you know, just doing stuff on his phone so that he's not really paying attention to what's going on around him" (p. 4). Participant 18 also reported that her son used toys to cope

and would seek others to involve others in his play to help with distraction. She describes this in the following exchange:

"Interviewee: He'll ask to play with his toys.

Interviewer: Okay. Did it calm?

Interviewee: Or he'll say, "Can we play a game?" or "Can I watch one of my movies?" or something like that. Something." (p. 27)

Although the distractor varied by participant report, some preferred electronic devices such as game boys and television, while others tended towards non-electronic distractors, such as books and Lego. No specific patterns emerged as to how the participants chose their distractors, but every participant reported distraction to be a useful for their child.

Be prepared. The second coping strategy that mothers observed their son's to engage in, involved preparing for the fear situation or experience. Mothers shared stories about how their sons would attempt to prepare themselves for facing an anxiety-provoking situation by gathering information, problem-solving or overly preparing for an event. Participant 2 noted that her son does better "so long as he's mentally prepared for what happens and it doesn't get too confining, it doesn't push him to far beyond what he can handle, then he can mentally talk himself through it he's okay with it" (p. 4). Participant 9 noted that she will "have written down a series of steps as to what to do" (p. 26) in order to help her son adapt to situations that cause him anxiety. Participant 14 noted that at school, her son uses a planner with all his school-work and information in it to help him reduce his anxiety when he transitions between classes. She reported "I think he tries to manage it a little bit by taking his binder with him everywhere he goes . . . He thinks that maybe if he has that, he'll be prepared for anything" (p. 59).

Participants also reported that their sons would over prepare for anxiety provoking events, such as exams or new experiences. Participant 11 noted that prior to exams her child would spend large amounts of time studying. She noted, "He makes sure and study the night before . . . and then he studies in the morning, packs his backpack. And I think he gets up early because he's afraid to sleep in" (p. 45). In another example, Participant 16 noted that her son will want to problem solve all the things that could go wrong before he completed a new task. She reported, "we talked about, "What if somebody drops the tray, what do you do? What if somebody, little kids try to do something weird, what do you do?" We talked through a lot of different situations" (p. 28). Participant 5 shared how to help assuage her son's fears of the house being robbed by allowing him to check the doors before they left to make sure they were locked and by "leaving the radio on" (p. 5). She stated, "we have to coax him through, talk him through" leaving the house (p. 5). Overall, mothers acknowledged that increasing their child's knowledge about a situation or experience could help improve their child's ability to cope.

Theme 5: Children with ASD Experience Physical Symptoms with Their Anxiety

When participants were asked if their child exhibited any physiological symptoms when anxious, a wide variety of symptoms were reported, from increased breathing to headaches. However, three symptoms emerged as themes: tension, restlessness and changes in the sympathetic nervous system.

Tension. Participant 14 summed up the general consensus of the group with the statement "yeah, anytime he gets anxious, he tenses up" (p. 36). Participant 19 noted that she can tell when her son is anxious because, "his muscles were really tight in his face and all over his body too" (p. 15). Participant 5 reported that when her son was anxious, "if you would have touched his shoulders they would have been rock hard" (p. 17). Participant 1 stated that she can tell her son is anxious just by looking at him. She notes, "the way he was standing he hunches his

shoulders and keeps his arms in close, kind of hugs himself when he is anxious in a situation" (p. 18). Of note, there was universal agreement among mothers that this tension causes significant discomfort in their children.

Restlessness. Another physical symptom that participants noted in their children was restlessness. Participant 10 stated that when her son becomes anxious he is "more tense than usual, he would walk irritated. He paces a lot. He'll get up in the classroom and start pacing" (p. 8). In addition to pacing, Participant 8 noted that her son "gets more fidgety . . . he's stands, he rocks, he spins, he fiddles with things. I've learned to give him things to fiddle with" (p. 65). Participant 20 had a similar description of her son. She reported, "when he's anxious, he kind of, he more fidgety than normal" (p. 17). Participant 9, reported that her son "cannot stand still" when he is anxious and he can be seen "pacing quickly" (p. 16) until his anxiety resolves. Participant 15 described her son as "jittery and jumpy" and reported that when anxious her son can also be seen "pacing back and forth" (p. 21).

Sympathetic nervous system changes. The final physiological symptoms that the participants noted in their children were changes in the sympathetic nervous system. Although no specific change emerged as a clear leader, mothers universally described various changes in the sympathetic system, such as changes in heart rate, breathing, as well as sweating. Participant 7 noted that when her son is anxious he could "having trouble breathing" and at times he even appeared to be "hyperventilating" (p.17). Participant 9 also reported that her son experienced "racing heart, headache, feeling like he is going to pass out sometimes" and noted, "he calls me probably eight times a week saying that his heart is racing" (p. 15). Participant 17 found that when anxious her son "tends to sweat a lot" and reported that if her son is anxious "he probably has sweaty palms" (p. 19). Participant 19 noted similar findings as she stated that when anxious

her son "feels like he can't breath and he'll sweat" (p. 34). She stated that her son would say to her "Mom, I can't, I feel like I can't breathe" (p. 45).

Theme 6: Anxiety and Anxious Thoughts Go Together

In order to gain a better understanding of what thought processes may be underlying a child's fear and anxiety, participants were asked what their child was thinking leading up to or during the anxious experience. Three specific themes emerged as mothers talked about what understood their child to be thinking: fear of failure, fear of social judgment and fear of uncertainty.

Fear of failure. Mothers talked about how from their perspective, their children seemed to be afraid of making mistakes or not doing something in just the right way. Participant 2 shared the following story:

"They were doing the eye exam and I think it was Participant M, he was starting get really, really anxious. I'm trying to figure out why and suddenly I realize he's trying to get all the answers right because they make you read all the letters off the chart and he couldn't see the letters, he needed glasses. He couldn't see the letters and he was so afraid of getting it wrong that he couldn't answer when they asked him, "What do you see?" So that was when we had to point out to him it's okay to—Answer is, "I can't see them" and that's an okay answer too. So it's all this I have to get everything right" (p. 16).

Participant 8 noted that when her son is anxious, he feels "like a failure . . . like he's not strong enough" (p. 11) to accomplish the task. Participant 1 stated that her son "worries that he would make a mistake" (p. 47) and as a result avoided feared activities. Participant 12 echoed this when her she described her son as avoiding trying new things because of a "fear of feeling like he won't be able to do it" (p. 16). Mothers also described how their sons were afraid of not being able to do perfectly on a task. When asked what she believed her son's underlying fear to

be she replied, "What's the worry? Probably just self-doubt or like he doesn't have the confidence enough to know that it's okay if it's not perfect. I think he is just innately a perfectionist in some things" (p. 20) She went on to describe how when her son participates in group activities he will often make statements such as "I'm no good enough. I'm not contributing to the team" (p. 33). Participant 5 stated that while her son may not avoid anxiety-provoking situations, making mistakes causes significant distress. She tells, "he'll get the word incorrect and sometimes, he's so frustrated. It's like he's rather not even try" (p. 19) She further noted that he will sometimes say, "why try? If I'm not going to get them all right anyway" (p. 24). Fear of failure at school was also common, with Participant 11 describing how prior to school exams her son will become anxious and "he is basically thinking, I'm going to fail" and went on to say that during these times her son would test her saying, "I am so stupid" (p. 26).

Fear of social judgment. The second theme that mothers perceived of as the underlying fear causing their child's anxiety was a fear of negative peer judgment and/or rejection. Group activities were reported to be especially hard for these children for this reason. When asked why her son was anxious during group activities, Participant 4 replied,

> "I think part of it was that he feels different from the other kids and maybe the teasing, and I think everybody watching him scared him and the fact that there's other kids maybe there that do tease him and that they would laugh at him I think has a big part of it because he did express that" (p. 6).

Participant 9 noted that her son is "scared of making a fool of himself" (p. 8). This was echoed by Participant 17 when she stated that her son was afraid, "he would look foolish. He didn't want to be the center of attention in class and have everyone looking at him" (p. 13)

Mothers expressed how their children would sometimes come to them and express their fears of others judging them. Participant 10 shared how her son wasn't able to do desired activities because of how others might view him. She shared, "This really is an issue. He would talk to me, he's so conscious of being embarrassed that he doesn't want to stand out in the class. Because he would go to the library during recess but he doesn't want to be seen as a retard" (p. 34). Participant 1 noted that anytime her son enters a social situation "he worries that he would inadvertently do something that would offend somebody" (p. 46) and has been heard to say, " What if I hurt someone's feelings? What if I do something embarrassing and I don't realize that it's embarrassing and everyone might laugh at me?" (p. 54). Participant 11 shared, "I don't know if you've ever read The Velveteen Rabbit but he doesn't feel real? He doesn't have anybody that talks to him like he's a real person" (p. 63). Participant 13 summed up the this principle by sharing that her son had told her, "I don't want to be different" (p. 61)

Fear of uncertainty. The final theme that arose when mothers described what their children's underlying fears could be, was fear of the unknown, or in other words, uncertainty. Participant 2 reported the following, "It's the fear of the unknown, I think, is the mostly what he's worried about . . . He likes to know what's coming, he likes to know what to plan. So it's mostly, I think it's the unexpectedness of it that's the issue for him" (p. 30). She went on to share a story about a last minute vacation the family took, that wasn't planned. She spoke of how each day they would decide what to do for activities in the morning, and sometimes not until moments before. She reported the result,

"On about day three or four of the vacation, he just couldn't deal with it anymore because he didn't know what to expect, he didn't know what was going to happen, he

didn't know what he was going to have for dinner. He wasn't sure which bed he was going to get to sleep in that night, I mean those kinds of things" (p. 56).

The other participants described similar fears in their sons. Participant 19 noted that when her son faces a new situation, there is anxiety due to there being "too much unpredictability" (p. 13). This was echoed by Participant 3 as she reported that when her child was anxious it was because of "not know what's gonna happen next. Just kinda that uncertainty" (p. 45). Participant 14 reported that when her son is "away from everything he's familiar with" he is especially anxious (p. 36). Participant 1 reported that when facing new and unfamiliar situations her son had "obsessive thoughts of what's to come" and further noted that "he's a worst case scenario kind of guy, anything new" (p. 78). Participant 6 shared how when her son started a new school he would constantly ask questions such as, "Well, what if you're not there when I got home? What if something happened during the school and I couldn't get to you?" (p. 1). Participant 9 said it best when she noted that the root of her son's anxiety was "something not happening the way he thought it should happen" (p. 4).

Theme 7: Mothers Can Identify the Etiology of Their Child's Anxiety

Another area that was explored with the participants was what they believed explained the emergence of their child's fear, or in other words, the etiology of the anxiety. Two major themes emerged during the exploration of this topic. The first theme centered on the presence of social difficulties (e.g., bullying) and increased social awareness. The second theme that emerged as mothers discussed what they believed to why their son's fear emerged was the idea that growing older and having increased responsibilities caused the emergence of the fear.

Social difficulties & awareness. Every participant talked about the impact social difficulties had on the emergence of their child's fear. The social difficulties were defined in a couple of ways. Some mothers talked about how their child was bullied by peers of other family

members, while others noted that theirs sons had trouble connecting with their peers. Participant 7 reported that her son's social anxiety emerged, "in the 5th grade" because "there was a boy that would bully him in his class" (p. 30). She also noted that around this same age, "friends that he'd always had started separating themselves from him" (p. 30). Bullying was often the source of the problem was also reported by Participant 16 when she noted that her son's anxiety began when, "He was being teased a lot…on the playground, bullied a lot" (p. 9). Bullying by other family members was also reported as causing the anxiety to manifest itself. Participant 11 reported, "I think it started when his brother squashed his hopes and dreams of ever having a social life" (p. 60). She went to report that she has found her son "crying because he has terrible social skills" after altercations with his sibling (p. 62).

Many mothers described how this increased social awareness marked the beginning of their child's anxiety. For example, when Participant 15 asked what she believed caused the emergence of her son's anxiety, she reported that it was connected to "when he first started dealing with social situations" (p. 13). Participant 9 shared a similar report as she said the following, "he really wants friends and is getting to the age where kids really bully and that is really hard for him" (p. 7). She went on to explain that her son "is starting to understand social situations and he is starting to see how other people think, which is a good thing. And he is starting to want approval of other people and that causes him fear" (p. 14). Participant 8 reiterated this desire for approval from peers when she noted that her son's anxiety developed when, 'he is more socially aware [and] wanted friends more" (p. 18) She further explains that it was at this time "the kids are more social aware and they started picking on him" (p. 18). These stories exemplify how from the point of view of mothers, social difficulties and increased awareness can explain the emergence of their children's social anxiety.

Growing older/changes. Another reason that mothers gave to explain the emergence of their child's anxiety was growing older and the increased responsibilities and/or changes that come with age. Participant 12 reported that when her son was younger, "he didn't have very much homework. He didn't have a lot of other activities. I think that it was easier for him to balance. He didn't have any other cleaning responsibilities. I did all that for him. I guess he's getting older and having more responsibilities placed upon him. He has younger siblings now too, which adds to it" (p. 8). She went on to explain that his anxiety, "really started to get bad when he was 12, when he started junior high . . . this happy-go-lucky child I once knew laughed and smiled all the time, kind of went away. Out came this angry person when he was 12" (p. 15). Participant 11 told a similar story. She reported that her son's anxiety increased when he switched schools after moving with the family. She shared that her son believed that if the family hadn't moved from their original location he "wouldn't be a nobody" (p. 61). She described how her son "got tears in his eyes" and would frequently ask "why did we move?" (p. 71). Participant 19 shared a similar story. She reported that as her son got older and had to face changes in his school and daily routine the anxiety he has been having a more difficult time coping with his anxiety. She reported "it gets worse when there are changes in schedule and changes in routine, like we have to move or something like that" (p. 10). She indicated that her son will tell her "things are unpredictable right now. I don't feel safe" (p. 30). Participant 10 also noted that "going from elementary school to junior high school and puberty" caused significant anxiety for her son (p. 35).

Participant 3 also reported that while son had always been a little anxious, it increased significantly as her son grew older. She shared, "I think he's older, and so there are more things that he's exposed to, to worry about" (p. 32). Participant 11 reported the same when she shared

that "because he's getting older" her son's anxiety is getting worse. She blamed his increase in anxiety to a "kind of growing awareness" (p. 24). Participant 13 noted that as her son "matures and his thoughts are more refined. I think he just thinks about thinks about things that could rather hurt him as he gets older" (p. 87). Overall, growing older and the changes that comes with aging have a negative impact on the anxiety symptoms.

Theme 8: Children's Anxious Thoughts Are Perceived as Reasonable

The final question in the interview asked mothers if they believed that their child's anxious thoughts were reasonable. When this question was posited, every single participant reported that they believed their child's anxious thoughts to be at least slightly reasonable, if not very reasonable. When asked to account for why they believed their child's anxious thoughts were reasonable, participants noted that they believed that their child's anxiety to be reasonable due the child's condition of ASD. Participant 9 summed up why the participants in general found their child's anxiety to be reasonable. When asked how reasonable she found her son's anxiety to be on a scale of zero to four, zero being "not reasonable at all" and four being "totally reasonable," she stated the following, "for person without autism it's zero. For a person with autism is one" (p. 23). She goes on to say, "because he has so much anxiety that for him I can see it being reasonable" (p. 72). Of note, she reported her son's anxious thoughts to be reasonable regarding this situation, "probably a year ago, I had to run somewhere for 15 minutes, then I left son C and brother A in charge, and said,

> "I'll be right back, every stay inside the house, keep the doors locked, you can watch TV.
> If you're watching a TV show, I'll be back in 15 minutes." I came back, son C had his
> wooden martial art sword, and was pacing the floor back and forth, and had everybody
> hiding in the tub of the bathroom because he saw someone walk by on the side walk
> outside the house. And he was so sure that they were going to kill everyone. So, he got

them all hiding in the bathtub, and he was pacing outside... in the living room, to keep everyone safe." (p. 34)

This story explained her earlier comment of, "Have you every tried to get a babysitter for a fifteen year old?" (p. 15) when we discussed how anxiety impacts family life. When Participant 1 was asked if her son's anxious thoughts during church were reasonable, she stated, "I think in general most people don't have the same sensory experience at church that he has so it's hard to judge" (p. 63). She goes on to explain, "since we don't have that sensory experience, I don't think that we would consider it reasonable to be that uncomfortable at that situation, but him being him, I think it's reasonable for him to be distressed" (p. 56). Participant 11 made a similar statement when she explained that her son's thoughts are reasonable because she believed her son was a "slow processor" and "because of what he was experiencing . . . given his set of social skills" (p. 72). Participant 12 shared a similar opinion when she stated, "because just being around autistic children these few years I've learned that these children need, depending on how far into the spectrum they are, they need to have some provisions, like he needs to have his down time, so I think that they're very reasonable" (p. 21). Along a similar note, Participant 4 noted that her son's emotional condition made his anxious thoughts reasonable. She stated,

" He is a very emotional type of person and I just – and, kinda sensitive and he kinda puts his guard up to other people so you wouldn't – sometimes, you don't see that because he kinda comes off like, "I'm in charge," and things like that. I think it's reasonable for him because he's got that emotional kind of almost like a disability where he doesn't know how to deal with it . . . So I think that it was reasonable that he felt that because he is not capable of dealing with his emotions." (p. 6)

Participant 20 also found her son's anxious thoughts to be understandable. She stated, "Because I can understand him maybe being embarrassed or not wanting to be there but to be extreme it was reasonable to me . . . I understand from his perspective why he was upset about that" (p. 19). She further explained the reasonableness of his anxious thoughts during a doctor's appointment by noting,

> "well just that it was something he'd never had to do before He didn't – he just, I guess,
> didn't know what to expect or why they were doing it, or whatever, even though they had
> explained it to him, you know. That was scary." (p. 19)

Although interesting that the mothers in this study rated their children's anxious behaviors as "slightly reasonable" to "very reasonable" due to their ASD diagnosis, it should be noted that theme only emerged because mothers were specifically asked if they found their child's anxious thoughts and behaviors were reasonable, and then asked to explain why they found it reasonable. Thus, this theme may not have developed had the question not been specifically asked. However, why mothers would choose to label their child's anxious thoughts as even "slightly reasonable" due to their condition of autism is an area that may benefit from future exploration.

Summary

In this section, I presented the findings of the study. These findings are based on the analysis of interview transcriptions. Findings were discussed based on the major themes that emerged from questions discussed in the interview. The major themes emerged under the categories of: family and individual interference, anxious actions, coping strategies for anxiety, physical symptoms of anxiety, anxious thoughts, etiology of anxiety and reasonableness of the anxious thoughts.

Mothers universally reported that the anxiety their children experience causes significant interference in family life by forcing the family to adjust and make changes to schedules and routines, demanding increased time, and by placing an emotional demands on family members. Anxiety was also found to have a negative impact on the child's life, by limiting what the child could do. Mothers also reported that they could clearly identify when their child was anxious through the following means: increased avoidance, changes in mood and affect, and physical aggression.

Participants were also able to describe coping strategies that their child engaged in to improve anxious symptoms. Distraction techniques and being prepared were the two themes that emerged for this topic. Participants reported that the themes underlying their child's anxious thoughts were a fear of failure, a fear of social judgment and a fear of uncertainty. Mothers also reported that their child's fear most likely developed either due to social difficulties and increased awareness and/or growing older and adjusting to the changes that come with age. In short, mothers were able to describe both the symptoms of their child's anxiety as well as give rich and full descriptions of the day-to-day challenges they face in helping their child cope with their anxiety.

Discussion, Recommendations, and Limitations

The purpose of this study was to examine the day-to-day presentation of anxiety in the high-functioning autistic population from the perspective of mothers. The interview sought to better understand how mothers perceive their child's anxious thoughts, emotions, feelings, beliefs, and actions, as well to understand the level interference caused by the anxiety for both the family and the individual child. This was achieved by administering a semi-structured interview to mothers with children on the autism spectrum. This section aims to review and

discuss the findings of this study. This study also discusses the implications of the finding and concludes with suggestions for further research.

These were the fundamental questions that framed this research:

1. What themes emerge in mothers' descriptions of a child/adolescent's: emotions, actions, physiological arousal, and thoughts for a specific anxiety symptom or situation?

2. What do mothers attribute as being the source of their child's anxiety?

3. In what way do anxiety symptoms interfere with the child's/adolescent's life and family life on a day-to-day basis?

4. What methods do mother observe their children using to cope with their anxiety?

The research questions were answered by the themes that emerged from the interview data reported in results section of this paper. How these themes align with current research is explored below.

Theme 1: Anxiety Symptoms in a Child with Autism Negatively Impact the Whole Family

It is well recognized that parenting a child with autism is source of significant stress for families (Wang, et al. 2013). It is also well-established by the literature that parenting a typically developing child with anxiety adds to family and maternal stress (Moore, Whaley, & Sigman, 2004). Moore, Whaley and Signman (2004) found that mothers were less warm to their anxious children regardless of the presence of maternal anxiety. They also found that mothers of anxious children were more likely to catastrophize, independent of their own personal anxiety levels. These researchers explained this finding by stating the following "Simply put, nonanxious mothers of anxious children were likely to predict disasters, perhaps as a result of their knowledge of their child's tendency to react anxiously" (Moore, Whaley, & Sigman, 2004; p. 9).

Given that parenting children with autism and parenting typically developing anxious children are stressful undertakings, it is not surprising that the mothers in this study reported

experiences that are in line with the current research. For this particular study, family interference was described in three different ways: changes in the family schedule, time demands and emotional toll on the mother and/or family. Participant 10, summarized this principle when she stated, "our family revolves around him" (p. 15). It should be noted that participants were asked to describe the interference caused by the anxious symptoms and not the core autistic symptoms. However, as the relationship between anxious and autistic symptoms is still unclear, it would be presumptions to assume that mothers were able to parse apart interference caused by their child's anxiety versus interference cause by their child's autism. Nonetheless, the mothers in this study recognized anxiety as a significant source of interference.

Theme 2: Anxiety Interferes with the Child's Life

Wood and Gadow (2010) suggested that the core symptoms of ASD can create stressful situations in a child's life and these stressors make a child with ASD more prone to developing anxious symptoms, which further reduces their overall quality of life. Eussen, et al. (2012), found that with lower symptoms of anxiety, adolescents with autism were able to increase the quality of their social relations. This suggests that increased levels of anxiety reduce the overall quality of their social relationships. In this study, mothers universally reported that their children's anxious symptoms significantly impacted their life by imposing limits on what their sons felt comfortable engaging in. Stories were shared about how anxiety can influence their children to avoid a variety of social activities and situations, which supports the research conclusions of Eussen et al. (2012). Participant 12 said it best when she reported, "Because he, his anxiety, the anxiety just causes him to not enjoy life" (p. 23). As mentioned above, in this interview mothers were asked to only describe the distress caused by the anxious symptoms their son experienced and not the distress that was due to the core features of autism. However, it unlikely that autism features could truly be separated from anxious features. Thus, this question

may not accurately capture the level of distress caused by anxious symptoms. It may be helpful in the future to compare how mothers of autism respond to these questions to how mothers of anxious children respond to these questions. Should a difference in their response themes emerge, it may indicate that distress caused autism can be

Theme 3: Mothers Can Identify Anxiety by Their Child's Anxious Behaviors

Participants in this study reported that they could recognize when their child was anxious by three specific behaviors: avoidance, changes in mood and affect, and aggression. Avoidance is a behavior that is a well-established symptom of anxiety. For example, one criterion for Separation Anxiety is "a persistent reluctance or refusal to go out, away from home, to school, to work or elsewhere because of fear of separation" (American Psychiatric Association, 2013). Additionally, in order to meet criteria for Social Anxiety Disorder an individual must be observed to avoid -or desire to avoid - social situations. Research has supported the idea that avoiding a feared stimulus serves to maintain and reinforce the fear and anxiety (Lejuez et al., 2002). In line with this research, participants in this study described avoidant behaviors as a sign of the child's anxiety. Stories were shared about how they have observed their children to avoid social situations or procrastinate completing tasks that provoked feelings of anxiety. Participant 5, for example, shared that when her son was anxious about going to school "his tactic was total avoidance" (p. 10).

In addition to avoidance, anxiety disorders have also been associated with changes in affect. For example, when describing the behaviors associated with Specific Phobia and Social Anxiety Disorder, DSM-V notes that children may express their fear through tantrums, clinging, or crying (American Psychiatric Association, 2013). Giles et al. (2015) found that healthy participants reported mood disturbances following participation in a stressful condition that involved a challenging test. Mood disturbances reported included increases in anger, tension, and

confusion following their participation in the stressful condition. These same disturbances were not reported when participants completed the alternative, non-stressful condition. The mood and affect changes described by the participants in this study included observations of their children crying and becoming angry in response to anxiety. Participant 5 offered this description of her child's changes in affect and mood when anxious, "It's like the gloves come off when they're at home and all you see are the raw, naked emotions but it's like sometimes you don't even see that, you just see the nasty behaviors" (p. 11).

It should be noted that a review of the current literature could not identify studies that demonstrated the degree of mood disturbance, reported by the mothers in this study, with other similarly aged, anxious, typically developing children and adolescence. This suggests that changes in mood and affect may be a promising avenue of questioning when assessing for anxiety in the high-functioning autistic population.

Limited research has been down to examine the interrelations between aggression and anxiety in children with ASD. However, Hagopian et al. (2013) found that children on the autism spectrum were more likely to engage in aggression and other problem behaviors to avoid feared or undesirable situations. Reid, Salmon and Loivbond (2006) found that cognitive biases such as hypervigilance to threat and negative interpretations of social events had significant links between anxiety and aggressive behaviors. More recently Nidithc, Varella, Kamps and Hill (2012) sought to understand the relationship between aggression and social understanding in toddler, pre-school and elementary school aged children with ASD. Their research found that increased social understand and higher rates of aggression were related to higher rates of anxiety in toddler-aged children. In their preschool and elementary school aged children either increased social understanding or higher aggression drove increased levels of anxiety. The qualitative

reports from this study suggest that aggressive behaviors are correlated to anxiety in the high-functioning autistic population. Participant 8 provided the following description of her son's aggressive behaviors when anxious, "He'll run, he will hit . . . he'll throw things at you. He just explodes and he even describes it that way. He also says it's inside me and it has to get out" (p. 5). Although aggression has been linked to anxiety in ASD, the relationship between anxiety and typically-developing children/adolescence is not as well-established. Overall, it appears that the profile of anxious behaviors in children and adolescents with ASD described by the participants in this study (e.g., avoidance, changes in mood and affect, and aggression) has been at least partially supported by the current literature.

Theme 4: Children with ASD Utilize Distraction and Preparation as Coping Strategies

Distraction and being prepared were the two coping strategies identified by the participants as being the most often used when anxious. Coping strategies are believed to play an important role in either helping a child to maintain or to overcome his anxiety. Various helping and harmful coping strategies have been identified by the literature. Compas et al. (2001) identified two proactive coping skills, support seeking and problem solving, as two strategies that were important for wellbeing. Avoidance and distraction are two strategies that have been identified as being associated with maladjustment (Skinner, Edge, Altman & Sherman, 2003). Based on the themes that emerged from this study, children with high-functioning autism appear to utilize both proactive and maladaptive coping strategies.

Distraction, considered to be a maladaptive coping strategy, included the use of both electronic and non-electronic devices. Legos, books, video games and television were some of the more common distractors that participants described as their child's go-to distraction tool when anxious. The more positive coping strategy that emerged as a theme was "being prepared." For this strategy, participants described how their children would try to gather information and

prepare for the anxious event. Mothers shared stories about how their child would practice a performance multiple times, and would ask questions about an event or situation to try to better understand what to expect. As Participant 2 shared, "so long as he's mentally prepared for what happens and it doesn't get too confining, it doesn't push him to far beyond what he can handle, then he can mentally talk himself through it he's okay with it" (p. 4). This may be a useful area to explore further, as helping parents and children with ASD to focus their efforts on more positive coping strategies may be the extremely helpful for treatment successfully treating the anxious symptoms.

Theme 5: Children with ASD Experience Physical Symptoms with Their Anxiety

It is well a well understood that anxiety symptoms include physiological responses. Generalized Anxiety Disorder, for example, lists fatigue, restlessness and muscle tension as possible symptoms. Anxiety has been found to activate the sympathetic nervous system, which activates the "flight or fight" response (Willmann, Langlet, Hainut, & Bolmont, 2012). Panic Disorder, for example, is a diagnosis used to describe individuals who experience recurrent panic attacks, and are characterized by a strong physiological response to anxiety. Symptoms include, but are not limited to: pounding hear, sweating, trembling, shortness of breath, etc. (American Psychiatric Association, 2013). Generalized Anxiety Disorder is associated with muscle tension (American Psychiatric Association, 2013).

In this study, participants consistently described their children as experiencing the following physical symptoms: tension, restlessness, and activation of the sympathetic nervous system. All of these symptoms are consistent with physiological symptoms that have been established as being associated with anxiety (American Psychiatric Association, 2013). Descriptions of tensing up when anxious and/or becoming more fidgety and restless in response to presence or thought of an anxiety provoking situation or stimuli were reported by the majority

of participants. As Participant 14 noted, "yeah, anytime he gets anxious, he [her son] tenses up" (p. 36). Participants also described how their children would pace when anxious.

Participants' description of changes in the sympathetic nervous system was slightly more variable. One parent might describe how her child was lightheaded when anxious (Participant 9) while another might describe changes in breathing (Participant 7). This difference in sympathetic nervous system is consistent with the current research literature as Willmann, Langlet, Hainaut, and Bolmont (2014) reported that there was a lack of "consistent physiological patterns" in anxiety profiles. These physiological symptoms should be explored further as it may serve to guide an anxious response profile for children with high-functioning ASD.

Theme 6: Anxiety and Anxious Thoughts Go Together

Three themes for anxious thoughts emerged when mothers were asked about what thoughts may be driving their child's anxious symptoms: fear of failure, fear of social judgment and fear of uncertainty. Each of these underlying themes has been addressed by the literature in the ASD population.

South, Dana, White and Crowley (2010) found that anxiety served as a moderator for risk taking behavior in children with ASD, due to an underlying fear of failure. In this study participants were given a modified version of the Balloon Analogue Risk Task (BART) to complete. This task required participants inflate balloons by choosing to the number of "pumps" a balloon will receive. Each pump was worth one point and the goal was too earn as many points as possible. The experimental factor was that each balloon was preset to explode at a random number between the first or 128th pump and if the balloon exploded the participant would lose all the points for that balloon. Risk taking behavior was measured by the number of pumps a participant gave each balloon. Surprisingly, participants with ASD engaged in higher levels of risk-taking behavior as the level of reported anxiety increased. This result was interpreted as

follows, "high anxiety in the ASD group leads to increased motivation due to a fear of failure." Participants in this study also noticed that fear of failure was common tenor for their child's anxious thoughts. Fear of making a mistake or not doing something "just-right" were the types of fears commonly expressed by their children. As participant 1 noted, her son avoids feared or new situations due to "worries that he would make a mistake" (p. 47).

Another common theme that participants described as the source of anxiety for their autistic children was a fear of social judgment. Kuusikko et al. (2008) administered a modified social anxiety questionnaire to high-functioning autistic participants, in which items that described the core symptoms of autism were removed. Even with those items removed, participants on the autism spectrum reported significantly more symptoms of social anxiety and engagement in avoidant strategies due to social anxiety in comparison to their typically developing peers. Participants' descriptions of how their child's fear of negative evaluations from their peers increased their avoidance of social situations and events are concordance with this current research.

Fear of uncertainty was the final theme that emerged when the participants described their child's anxious thoughts. This fear of uncertainty has been given the name the "intolerance of uncertainty" by the literature and is an area that has received some attention in the research. Defined by Carleton et al. (2002, p. 939) the intolerance of uncertainty is understood to be "a broad dispositional risk factor for the development and maintenance of clinically significant anxiety." Boulter, Freeston, South and Rodgers (2013) modeled the relationship between anxiety and this principle within the ASD population to better understand how this fear of uncertainty may apply the presence of anxiety in ASD. Their results found that an intolerance of uncertainty mediates the relationship between ASD and anxiety. This suggests that higher levels of anxiety

are associated with higher levels of intolerance of uncertainty in the ASD population. From the analysis of this research project, participants reported that unpredictability and engaging in new and unknown activities was a significant stressor for their children; many noted that their children had verbalized this discomfort of not knowing what to expect. Participant 2 said it best when she noted, "It's the fear of the unknown, I think, is the mostly what he's worried about . . . He likes to know what's coming, he likes to know what to plan" (p. 31).

A research review was unable to determine if either of the underlying fears has a significant presence in the clinically anxious population. It may be helpful to compare the qualitative themes reported by this population to qualitative themes reported by a clinically anxious population to assess for differences. If differences emerge, it may indicate that underlying fears can help separate autism symptoms from anxious symptoms.

Theme 7: Mothers Can Identify the Etiology of Their Child's Anxiety

When the participants were asked what they believed explained the etiology of their child's anxiety, two major themes emerged: social difficulties and awareness and growing older and adjusting to the changes that come with age. Within the literature various theories have been purported to explain the development of anxiety. Anxiety by way of pavlovian conditioning is a widely accepted model of anxiety. Using this model, anxiety is the result of fear conditioning in which a neutral stimulus is paired with an aversive stimulus which results in the neutral stimulus becoming associated with fear (LaBar, Gatenby, Gore, LeDoux & Phelps, 1998). Fear is then reinforced by avoidance (Eysenck & Rachman, 1965). Of note, current models for the development of social anxiety disorder focus on the fear of experiencing social pain. Social pain is defined as the emotional state that person experiences real or potential damage to his or her sense of social connection (Mineka & Zinbarg, 2006). Participants from this study described what could be considered the experience of social pain in their children as the reason for the

development of anxiety. Teasing, bullying, rejection from peers were also reasons mothers offered to explain the onset of their children's anxious symptoms. Participant 16, for example reported that her son's anxiety developed when "he was being teased a lot . . . on the playground, bullied a lot" (p. 9).

Childhood and adolescence have been described as the "core risk phase for the development of symptoms and syndromes of anxiety" (Beesdo, Knappe & Pine, 2011, p. 483). Separation anxiety and types of specific phobia have been identified as having the earliest onset for anxiety disorders, as they typically develop prior to the age of 12-years. The onset of social anxiety disorder ranges from childhood to adolescence. Panic disorder, agoraphobia, and GAD typically develop in adolescence or early childhood (Beesdo, Knappe, & Pine, 2011). Although this study did not expressly diagnosis participants' children with an anxiety diagnoses, participants did describe how their child's anxious symptoms increased and worsened as they aged. As Participant 3 shared about her son's anxiety, "I think he's older, and so there are more things that he's exposed to, to worry about" (p. 32) Additionally, most mothers described how the anxiety seemed to be triggered by stressful situations, such as switching schools, which fits a diathesis-stress model of anxiety, which purports that a combination of vulnerability factors (diathesis) and stress experienced in a person's life result in the development of anxiety (Zvolensky, Kotov, Antipova, & Schmidt, 2005). Overall, the themes that emerged regarding the etiology of anxiety seem to be comparable to the research thus far.

Theme 8: Children's Anxious Thoughts Are Perceived as Reasonable Because of Their Condition

As previously discussed, when mothers were asked if their child's anxious thoughts or behaviors was reasonable, the responses ranged from identifying the thoughts as "slightly reasonable" to "very reasonable." Although there was the option to say "not reasonable" this

option was not chosen frequently and each mother found at least one example of their child's anxious responses to be at minimum "slightly reasonable." When asked why they found the anxious response to be reasonable, the theme that emerged was that the child's condition of autism. A review of literature was unable to identify other research studies that assessed parental perception of the reasonableness in their child's anxious thoughts. Although this concept – the reasonableness of anxious thoughts – has not been explicitly explored in the literature it presents as an interesting component to how mothers may perceive the anxious presentation of their children. It certainly begs the question of how perceiving anxious thoughts as reasonable may change how mothers treat, understand and think about their child's anxiety. It would be interesting to compare this response to a clinically anxious population in order to determine if mother's of anxious children are also willing to identify their child's anxious thoughts and behaviors as reasonable.

Recommendations for Future Research

Based on the report of the participants in this study, anxiety symptoms in high-functioning children and adolescents on the autism spectrum significantly impact the functioning of the family and the child. Day to day interference was endorsed and mothers regularly identified social stressors and change as the source of their child's anxious symptoms. Although some strategies were described as being helpful for reducing some anxious symptoms (i.e., using distractions or preparing) the tenor of the mothers reports indicated that these strategies were not always enough to reduce the symptoms to a manageable level.

The findings from this study point to several for future research in the area of anxiety in autism: (1) anxiety should be assessed and treated in the high-functioning autistic population; (2) research should endeavor to better understand how to differentiate anxiety from the core symptoms of autism; (3) research should continue to gain a better understanding of the

physiological symptoms, behavioral presentation and cognitive processes of anxiety in the autistic population for the purposes of assessment and treatment.

Recommendation 1: Assessing and treating anxiety in the autism spectrum population. Day-to-day descriptions and examples of how anxiety negatively and significantly impacted family and child life was a clear theme in this study. Additionally, participants clearly acknowledged their sons' anxieties as the source of the interferences and not the core symptoms of autism. Mothers shared stories of how they and other family members were not able to travel and participate in activities due to their child's anxiety. Stories were also shared describing the emotional toll and time demands placed on themselves and the family because of their child's anxious symptoms. Even simple tasks, such as going to church or running an errand can be challenging due to the child's anxiety. Participant 4 describes her child's anxiety anytime they have to leave the house:

"It causes a lot of frustration when trying to get him to comply with behaviors, like getting ready on time, stuff like that. And if he is just so over the top with his feelings about the burglary scenario or somebody breaking in, hurting his house or hurting his family, it's a big deal to him and it's disruptive to the whole family. It's like the girls really get frustrated with it. His dad gets frustrated with it. I get tired of it but then, I have to remind myself, I am the mom and I can't really... you know what I mean? So, I have to try and coax him through this" (p. 9).

In addition to holding their child's anxiety responsible for family interference, they also reported that anxiety significantly interfered with their son's life as well. They identified the anxiety as limiting what the child could do. Mothers described how anxiety stood in the way for their child developing social skills, relationships or comfortably engaging in new and different activities or situations. Participant 12 said it best in the statement "Because he, his anxiety, the

anxiety just cause him not to enjoy life" (p. 23).

Given the degree of interference anxiety is perceived to cause, treatment of the symptoms may play an important role in improving the quality of life for both children and family of children on the autism spectrum disorders. Although it is unclear how well these qualitative descriptions differentiate between the interference caused by anxious symptoms vs the interference caused by autistic symptoms, this study suggests that anxiety is viewed as a significant source of stress by mothers with children on the autism spectrum. As such clinicians working with this population should highly considered assessing for and treating anxious symptoms. Future research should also endeavor to better understand how anxiety-specific medication and treatment may improve symptoms.

Recommendation 2: Differentiate anxiety from core symptoms of autism for treatment. It is well worth noting that treating anxiety in the high-functioning autistic population is not possible unless the presence of anxiety can be detected. As all current measures of anxiety are designed for the typically developing population, no measures have validated for the autistic population. As such the psychometric properties (i.e., sensitivity and specificity) of the current measures have not been determined for the autistic population. This study noticed that qualitative reports did not always match the quantitative report. For example, Participant 12's response on the SCAS indicated a total score of 1, which suggests that her son does not present with any significant symptoms of anxiety. Despite this low score, note the following exchange that occurred during the interview:

"Interviewer: How much of your day do you spend calming this anxiety?

Interviewee: ... depending on how much time I have, I spend at least about an hour

managing him" (p. 10).

This discrepancy between what was reported on the anxiety measure versus what was reported during the qualitative interview highlights the current concerns regarding using unmodified anxiety measures to assess the ASD population. Although some effort has been made to modify current anxiety measures to make them more autism specific (i.e., Autism Co-Morbidity Interview – Present and Lifetime Version measure previously discussed), lack of agreement regarding how to differentiate the core features of autism from anxious symptoms has made this difficult. The answer to the question, is a child's avoidance of loud sounds, a feature of autism (i.e., hypersensitivity to sound) or is a specific phobia of loud noises, has still not been agreed upon in the literature.

Due to the lack of appropriate measures, continued qualitative research in this area is recommended. Additional studies should endeavor to understand the physiological, behavioral and cognitive presentation of anxious symptoms in the ASD population through interviews with fathers, siblings, teachers and the children themselves. By gathering data from multiple reporters, a full picture of the day-to-day presentation of anxiety in the high-functioning ASD population may be developed. The culmination of themes developed from such a process will provide the material required to develop questions that better capture the anxious presentation in the ASD population.

Recommendation 3: Physiological, behavioral & cognitive presentation of anxiety in autism. Clear themes describing the physiological, behavioral and cognitive presentation in this population emerged from this study. Physiological symptoms most commonly reported as observed symptoms were: tension, restlessness and changes in the sympathetic nervous system. Avoidance, changes in mood and affect and physical aggression where the most common themes for the behavioral presentation of anxiety. Fear of failure, fear of social judgment and fear of

uncertainty were the themes that emerged for the cognitive presentation of anxiety.

Interestingly enough, as noted in the section above, all of these themes have been identified as part of the anxious profile in autism and/or the typically developing population by previous studies. Future research should continue to explore these specific physiological, behavioral and cognitive symptoms, as a better understanding of these observable symptoms is important for both assessment and treatment purposes. A better understanding of these principles will guide treatment development. Understanding the underlying thought processes behind the anxiety is especially important for treatment as knowing the source of the fear and anxiety will allow for more individualized treatment. Treating a child for fear of dogs isn't particularly helpful if the child is actually afraid of cats.

Limitations

As with all studies, this research project presented with limitations that need to be addressed. Although we had a relatively large sample size for a qualitative study, only data from the mothers' point of view was collected as opposed to gaining insight from other members of the family or environment, such as fathers, siblings, teachers and children on the autism spectrum. Further, only mothers of male children were interviewed, and female children may present with a different anxious presentation. This significantly limited scope and the results should not be considered generalizable to the rest of the high-functioning autistic population. Additionally, there was limited variation in ethnic background of the participants, which also limits the generalizability of these results. It is important to remember that each mother's experience with her autistic sons' anxiety may greatly differ from one family to another.

It should be noted that mothers were asked to respond to the questions solely considering the child's anxious symptoms. However, it is presumptuous to assume that mothers were able parse apart their child's anxious symptoms from their core autistic symptoms. Thus, this study

cannot definitively state that the themes gathered from this study solely represent anxiety and are not influenced by core autistic features. Comparison studies (e.g., clinically anxious vs. clinically anxious ASD) will be necessary to further define and conceptualize the anxious presentation in autism.

Another limitation was that all the information gathered during the data collection process was dependent on the interviewee and what she as willing to share. Further, the information she shared was limited by her own life experiences and perspective. As this study utilized the process of triangulating the data to help control for this limitation, there is support for the accuracy of the themes that did emerge.

Conclusions

If there is one clinical application from this study, it is that anxiety should be assessed and treated in the high-functioning autistic population. Based on the report of the mothers in this study, anxiety is responsible for increasing parental and family stress, as well as limiting a child's ability to participate in a variety of activities, including social interaction, and school attendance. Clear themes emerged for the physiological, cognitive and behavioral presentation of anxiety, which suggests that continuing to develop an anxious narrative for this population will be a useful tool for developing an anxiety measure that is designed specifically for the high-functioning autistic population.

Of note, this study also suggests that current anxiety measures may not be appropriate as the sole source of diagnosing the presence of anxious symptoms in the autistic population. Several participants reported low scores on the Spence, only to have the interviews reveal significant and time consuming anxious symptoms in their children. As such, clinical interviews with the parents and the child may be a more helpful and accurate tool for identifying the presence of anxiety in this population. The cognitive themes that emerged from this study (e.g.,

fear of failure, fear of uncertainty, and fear of social judgment) as well as the physical symptoms (e.g., tension, restless and sympathetic nervous system) are areas that may be helpful to explore when completing a clinical interview. Treating the symptoms of anxiety are also clearly important, due to the level of stress the anxiety places on the family and the child. Tools such as distraction and preparedness were the two most commonly used coping strategies discussed by this group of mothers. It may be that using these two skills in a therapeutic setting may be helpful in gaining buy-in from the child and the parent and to help mothers feel that they are able to help to reduce their child's symptoms in some way.

References

Abbeduto, L., Seltzer, M., Shattuck, P., Krauss, M., Osmond, G., & Murphy, M.(2004). Psychological well-being and coping in mothers of youths with autism, Down Syndrome or fragile X syndrome. *American Journal of Mental Retardation, 109,* 237-254.

American Psychiatric Association.(2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: American Psychiatric Association.

American Psychiatric Association.(2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington: American Psychiatric Publishing.

Barlow, D.(2002). *Anxiety and its disorders: The nature and treatment of anxiety and panic* (2nd Edition). New York: Guilford Press.

Beesdo, K., Knappe, S., & Pine, D.(2009). Anxiety and anxiety disorders in children and adolescents: Developmental issues and implication for DSM-V. *Psychiatry Clinical North America, 32*(3), 483-524.

Ben Itzchak, E., Lahat, E., Burgin, R., & Zachor, A. D.(2008). Cognitive, behavior, and intervention outcome in young children with autism. *Research in Developmental Disabilities, 29,* 447–458. doi:10.1016/j. ridd.2007.08.003

Berger, S., Kouzarides, T., Shiekhattar, R., and Shilatifard, A.(2009). An operational definition of epigenetics. *Genes Development 23*(7), 781-783.

Bettelheim, B. (1967). *Empty fortress.* New York, NY: Simon and Schuster.

Bitsika, V., Sharpley, C., Sweeney, J., & McFarlane, J.(2014). HPA and SAM axis responses as correlates of self- vs parental ratings of anxiety in boys with an Autistic Disorder. *Physiology & Behaviour, 127*, 1–7.

Bleuler, E.(1950). *Dementia Praecox, or the group of schizophrenias* (trans: J. Zinkin). New York: International Universities Press. (Original work published in 1911).

Braun, V. & Clarke, V.(2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101. doi: 10.1191/1478088706qp063oa

Brereton, A. V., Tonge, B. J., & Einfeld, S. L.(2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders, 36*, 863–870. doi:10.1007/s10803-006-0125-y

Caelli, K., Ray, L., & Mill, J.(2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods, 2*(2). *Article 1*. Retrieved from http://www.ualberta.ca/~iiqm/backissues/2_2/html/caellietal.htm

Caniato, R.(2007). Epilepsy in autism spectrum disorders. *European Child and Adolescent Psychiatry, 16*, 61–66. doi:10.1007/s00787-006-0563-2

Cartwright-Hatton, S., McNicol, K., & Doubleday, E.(2006). Anxiety in a neglected population: Prevalence of anxiety disorders in pre-adolescent children. *Clinical Psychology Review, 26*(7), 817–833.

Center for Disease Control.(2015). *Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network, United States, 2015.* Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

Chansky, T. E.(2004). *Freeing your child from anxiety*. New York, NY: Broadway Books.

Charman, T., Jones, C. R. G., Pickles, A., Simonoff, E., Baird, G., & Happe, F.(2011). Defining the cognitive phenotype of autism. *Brain Research, 1380*, 10–21.

Cholemkery, H., Kitzerow, J., Rohrmann, S., & Freitag, C.(2014). Validity of the social

    responsiveness scale to differentiate between autism spectrum disorders and disruptive

    behavior disorders. *European Child and Adolescent Psychiatry, 23*(2), 81-93.

Chorpita, B. F., Bernstein, A., & Daleiden, E. L.(2011). Empirically guided coordination of

    multiple evidence based treatments: An illustration of relevance mapping in children's

    mental health services. *Journal of Consulting and Clinical Psychology, 79*(4), 470–480.

    doi:10.1037/a0023982

Compas, B., Connor-Smith, J., Saltzman, H., Harding Thomsen, A.,& Wadsworth, M.(2001).

    Coping with stress during childhood and adolescence: Problems, progress, and

    potential in theory and research. *Psychological Bulletin, 127*, 87–127. doi: 10.1037/0033-

        2909.127.1.87

Cooper, S., & Endacott, R.(2007). Generic qualitative research: A design for qualitative

    research in emergency care*? Emergency Medicine Journal, 24*, 816-819.

Cooper, Harris (Ed); Camic, Paul M. (Ed); Long, Debra L. (Ed); Panter, A. T. (Ed); Rindskopf,

    David (Ed); Sher, Kenneth J. (Ed), (2012). *APA handbook of research methods in*

    psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and

    biological. (pp. 57-71). Washington, DC, US: American Psychological Association.

de Alba, M. G., & Bodfish, J. W. (2011). Addressing parental concerns at the initial diagnosis of

    an autism spectrum disorder. *Research in Autism Spectrum Disorders, 5*(1), 633-639.

    doi:10.1016/j.rasd.2010.07.009

Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in

    mothers of children with autism. *Autism, 9*(4), 416–427. doi:10.1177/1362361305056081

DuPont, R. L., Rice, D. P., Miller, L. S., Shiraki, S. S., Rowland, C. R., & Harwood, H. J.(1996). Economic costs of anxiety disorders. *Anxiety, 2*(4), 167–172.

Eysenck, H. J., & Rachman, S. J.(1965). *Causes and cures of neurosis*. London: Routledge & Kegan Paul.

Falkmer, T., Anderson, K., Falkmer, M., & Horlin, C.(2013). Diagnostic procedures in autism spectrum disorders: A systematic literature review. *European Child & Adolescent Psychiatry, 22*(6), 329-340. doi:10.1007/s00787-013-0375-0

Fombonne, E.(2009). Epidemiology of pervasive developmental disorders. *Pediatric Research, 65*(6), 591–598.

Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M.(2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology and Health*, *25*, 1229–1245. doi:10.1080/08870440903194015

Frans, EM., Sandin, S., Reichernberg, A., Langstrom, N. Lichenstein P., McGrath, J.,& Hultman, C.(2013) Autism risk across generations: A population-based study of advancing grandparental and paternal age. *Journal of American Medical Association Psychiatry, 70,* 516-521.

Freelon, D.(2010). ReCal: Intercoder reliability calculation as a web service. *International Journal of Internet Science, 5*(1), 20-33.

Gandy, M., Sharpe, L., Perry, K., Miller, L., Thayer, Z., Boserio, J., & Mohamed, A.(2013). Rates of DSM-IV mood, anxiety disorders, and suicidality in Australian adult epilepsy outpatients: A comparison of well-controlled versus refractory epilepsy. *Epilepsy & Behavior, 26*(1), 29-35.

General Medical Council. (2010). *Andrew Wakefield: Determination of serious professional misconduct* (PDF) Retrieved from: www.gmck.org/Wakefield_SPM_and_SANCTION.pdf_32595267.pdf

Ghaziuddin, M.(2002). Asperger syndrome: Associated psychiatric and medical conditions. *Focus on Autism and Other Developmental Disabilities, 17*, 138-144.

Giles, G., Mahoney, C., Urry, H., Brunye, T., Taylor, H., and & Kanarek, R.(2015). Omega-3 fatty acids and stress-induced changes to mood and cognition in healthy individuals. *Pharmacology Biochemistry and Behavior, 132,* 10-19.

Gotham, K., Bishop, S., Hus, V., Huerta, M., Lund, S., Buja, A., & Lord, C.(2013). Exploring the relationship between anxiety and insistence on sameness in Autism Spectrum Disorder. *Autism Research, 6*, 33–41.

Grandy, M., Sharpe, L, & Perry, K.(2013) Cognitive behavior therapy for depression in people with epilepsy: A systematic review. *Epilepsia, 54*(10), 1725-1734.

Grills, A., & Ollendick.(2005). Fears in children and adolescents: Reliability and generizability across gender, age and nationality. *Behavior Research Therapy, 27*(1), 19-26.

Harper, A., Dyches, T., Harper, J., Roper, S., & South, M.(2013). Respite care, marital equality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43,* 2604-2616.

Hartley, S., Barker, E., Seltzer, M., Floyd, F., Greenberg, J., Orsmond, G. & Bolt, D.(2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24*(4), 449-457.

Hartley, S. L., & Sikora, D. M.(2009). Which DSM-IV-TR criteria best differentiate high-functioning autism spectrum disorder from ADHD and anxiety disorders in older children? *Autism: The International Journal of Research and Practice, 13*, 485–509.

Horvath, K., & Perman, J. A.(2002). Autism and gastrointestinal symptoms. *Current Gastroenterology Reports, 4,* 251–258.

Hoyt, W., & Bhati, K. (2007). Principles and practices: An empirical examination of qualitative research in the Journal of Counseling Psychology. *Journal of Counseling Psychology, 54*, 201-210. doi:10.1037/0022-0167.54.2.201

Jamieson, R., McConachie, H., & Rodger, J.(2011). *Appendix B of SCAS Parent Interview*. (Unpublished thesis). Newcastle University, Newcastle, England.

Jha, P., Sheth, D. & Ghaziuddin, M.(2007) Autism spectrum disorder and Klinefelter syndrome. *European Child Adolescent Psychiatry, 16*(5), 305-308.

Joseph, R., Ehrman, K., McNally, R., & Keehn, B.(2008). Affective response to eye contact and face recognition ability in children with ASD. *Journal of International Neuropsychological Society, 14*(6), 947-955.

Kazdin. A. (2003). *Research design in clinical psychology* (4th Edition). New York, NY: Harper & Row.

Kanner, L.(1943). Autistic disturbances of affective contact. *Nervous Child, 2*(3), 217–250.

Kerns, C., Kendall, P., Berry, L., Souders, M., Franklin, M., Schultz, R., Miller, J., & Herrington, J.(2014). Traditional and atypical presentation of anxiety in youth with autism spectrum disorder. *Journal of Autism Developmental Disorder, 44*, 2851-2861.

King, M., & Bearman, P (2009). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology, 38,* 1224–1234. doi:10.1093/ije/dyp261

Kostere, K., & Percy, W. H.(2008). *Qualitative research approaches in psychology* (Rev. ed.). Minneapolis, MN: Capella University.

Kuusikko, S., Pollock-Wurman, R., Jussila, K., Carter,A., Mattila, M., Ebeling, & H., et al.(2008). Social anxiety in high-functioning children and adolescents with Autism and Asperger syndrome. *Journal of Autism and Developmental Disorders, 8*, 1697–1709.

LaBar, K., Gatenby, J., Gore, J., LeDoux, J., & Phelps, E (1998). Human amygdala activation during conditioned fear acquisition and extinction: A mixed trial fMRI study. *Neuron, 20,* 937–945.

Lai, M., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S.(2015). Sex/gender differences and autism: Setting the scene for future research. *Journal of The American Academy Of Child & Adolescent Psychiatry*, *54*(1), 11-24. doi:10.1016/j.jaac.2014.10.003

Lejuez, C., Read, J., Kahler, C., Richards, J., Ramsey, S., & Stuart, G.(2002). Evaluation of a behavioral measure of risk-taking: The balloon analogue risk task (BART). *Journal of Experimental Psychology: Applied, 8,* 75-84.

Lewin, A., Wood, J., Gunderson, S., Murphey, T., & Storch, E.(2011). Phenomenology of comorbid autism spectrum and obsessive-compulsive disorders among children. *Journal of Developmental and Physical Disabilities, 23*(6), 543-553.

Leyfer, O., Folstein, S., Bacalman, S., Davis, N., Dinh, E., & Morgan, J.(2006). Comorbid psychiatric disorders in children with autism: Interview developmental and rates of disorders. *Journal of Autism Developmental Disorders, 36,* 849-861.

Lombard, M., Snyder-Duch, J., & Bracken, C. C.(2002). Content analysis in mass communication: Assessment and reporting of intercoder reliability. *Human Communication Research, 28,* 587-604.

Lord, C., Petkova, E., Hus, V., Gan, W., Lu, F., Martin, D. M., et al.(2012). A multisite study of the clinical diagnosis of different autism spectrum disorders. *Archives of General Psychiatry, 69*, 306–313. doi:10.1001/archgenpsychiatry.2011.148

Mash, E. & Wolfe, D.(2005). *Abnormal child psychology* (3rd Edition). Boston, MA: Cengage Learning Center.

Matson, J., & Love, S.(1990). A comparison of parent-reported fear for autistic and non-handicapped age-match children and youth. *Australian and New Zealand Journal of Developmental Disabilities, 16,* 349-357.

Merikangas, K.R & Avenevoli, S.(2002). Epidemiology of mood and anxiety disorders in children and adolescents. In: M.T. Tsuang and M. Tohen, (Eds.), *Textbook in psychiatric epidemiology* (657-704), Wiley-Liss, New York.

McCarthy, J.(2007). *Louder than words: A mother's journey in healing autism*. New York: Penguin.

Mineka, S., & Zinbarg, R.(2006). A contemporary learning theory perspective on the etiology of anxiety disorders: It's not what you thought it was. *American Psychologist*, *61*(1), 10-26.

Morris, T. L., & March, J. S.(2004). *Anxiety disorders in children and adolescents* (2nd ed.). New York, NY, US: Guilford Press.

Moseley, D. S., Tonge, B. J., Brereton, A. V., & Einfeld, S.(2011). Psychiatric comorbidity in adolescents and young adults with autism. *Journal of Mental Health Research in Intellectual Disabilities, 4,* 229–243. doi:10.1080/19315864.2011.595535

Muris, P. & Field, A.(2008). Distorted cognition and pathological anxiety in children and adolescents. *Cognition and Emotions, 22,* 395-421.

Myles, B., Barnhill, G., Hagiwara, T., Griswold, D. & Simpson, R.(2000). A synthesis of studies on the intellectual, academic, social/emotional, and sensory characteristics of children with Asperger syndrome. *Education and Training in Mental Retardation and Developmental Disabilities, 36,* 304-311.

Niditch, L., Varela, R., Kamps, J., & Hill, T.(2012). Exploring the association between cognitive functioning and anxiety in children with autism spectrum disorders: The role of social understanding and aggression. *Journal of Clinical Child & Adolescent Psychology, 41*(2), 127-137.

Offit, P. (2008). *Autism's false prophets: Bad science, risky medicine, and the search for a cure.* New York: Columbia University Press.

Ollendick, T., King, N., Frary, R.(1989). Fears in children and adolescents. Reliability and generalizability across gender, age, and nationality. *Behavior Research & Therapy, 27,* 19-26.

Pugliese, C., White, B., White, S., & Ollendick, T.(2013). Social anxiety predicts aggression in children with ASD: Clinical comparisons with socially anxious and oppositional youth. *Journal of Autism and Developmental Disorder, 43*(5), 1205-1213.

Rahman, O., Reid, J. Parks, A., McKay, D., & Storch, E.(2011). Obsessive-compulsive disorder. In D. McKay & E. Storch (Eds.), *Handbook of child and adolescent anxiety disorders* (pp. 323-338). New York: Springer.

Reaven, J.(2009). Children with high-functioning autism spectrum disorders and co-occurring anxiety symptoms: Implications for assessment for treatment. *Journal for Specialist in Pediatric Nursing, 14*(3), 192-199.

Reid, S., Salmon, K., & Lovibond, P.(2006). Cognitive biases in childhood anxiety, depression, and aggression: Are they pervasive or specific? *Cognitive Therapy and Research, 30*, 531–549.

Renno, P, & Wood, J.(2013). Discriminant and convergent validity of the anxiety construct in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43,* 2135 – 2146.

Rotheram-Borus, M. J., Swendeman, D., & Chorpita, B. F.(2012). Disruptive innovations for designing and diffusing evidence-based interventions. *American Psychologist, 67*(6), 463–476. doi:10.1037/a0028180

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., et al.(2009). Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. J*ournal of the American Academy of Child and Adolescent Psychiatry, 48,* 474–483. doi:10.1097/CHI.0b013e31819b3848

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*, 921–929.

Skinner, E., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin, 129*, 216–269. doi: 10.1037/0033-2909.129.2.216

Smith, L., Hong, J., Seltzer, M., Greenberg,J., Almeida, D., & Bishop, S.(2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 40*, 167-178.

South, M., Dana, J., White, S. E., & Crowley, M. J.(2011). Failure is not an option: Risk-taking is moderated by anxiety and also by cognitive ability in children and adolescents diagnosed with an autism spectrum disorder. *Journal of Autism And Developmental Disorders, 41(1),* 55-65. doi:10.1007/s10803-010-1021

Spence, S.(1998). A measure of anxiety symptoms among children. *Behaviour Research & Therapy, 36*(5), 545–566.

Stake, R. E. (1995). *The art of case study research.* Thousand Oaks, CA: SAGE Publications.

Swedo, S. E., Baird, G., Cook, E. H. Jr., Happé, F. G., Harris, J. C., Kaufmann, W. E., et al.(2012). Commentary from the DSM-5 workgroup on neurodevelopmental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(4), 347–349.

Tuchman, R., & Rapin, I. (2002). Epilepsy in autism. *The Lancet Neurology, 1*, 352–358.

Turner, L., & Romanczyk, R.(2012). Assessment of fear in children with an autism spectrum disorder. *Research in Autism Spectrum Disorders, 6*, 1203-1210.

Turner-Brown, L., Lam, K., Holtzclaw, T., Dichter, G., & Bodfish, J.(2011). Phenomenology and measurement of circumscribed interests in autism spectrum disorders. *Autism: The International Journal of Research and Practice, 15*(4), 437-456.

van Steensel, F. A., Bögels, S. M., & Wood, J. J. (2013). Autism spectrum traits in children with anxiety disorders. *Journal of Autism And Developmental Disorders, 43*(2), 361-370. doi:10.1007/s10803-012-1575-z

Vasa, A., Kalb, L., Mazurek, M., Kanne, S., Freedman, B., Keefer, A. & Murray, D.(2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*(11), 1358-1369.

Vasey, M., & MacLeod, C.(2001). Information-processing factors in childhood anxiety: A review and developmental perspective. In M.W. Vasey & M. R. Dadds (Eds.). *The development of psychopathology of anxiety* (pp. 253-277). New York: Oxford University Press.

Velting, O. N., Setzer, N. J., & Albano, A. M.(2004). Update on and advances in assessment and cognitive behavioral treatment of anxiety disorders in children and adolescents. *Professional Psychology: Research and Practice*, *35*(1), 42.

White, S., Oswald, D., Ollendick, T., & Scahill L.(2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review*, *3,* 216-29.

White, S., Albano, A. Johnson, C. Kasari, C., Ollendick, T., Klin., A & Scahill, L.(2010). Development of cognitive-behavioral intervention program to treat anxiety and social deficits in teens with high-functioning autism. *Clinical Child and Family Psychology Review, 13,* 77-90.

White, S. W., & Schry, A. R.(2011). Social anxiety in adolescents on the autism spectrum. In C. Alfano & D. Beidel (Eds.), *Social anxiety in adolescents and young adults: Translating developmental science into practice* (pp. 183–201). Washington, DC: American Psychological Association.

White, S. W., Schry, A. R., & Maddox, B. B.(2012). Brief report: The assessment of anxiety in high functioning adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 42,* 1138-1145. doi: 10.1007/s10803-011-1353-3

Whittemore, R., Chase, S., & Mandle, C. (2001). Validity in qualitative research. *Qualitative Health Research, 11*(4), 522-537.

Wigham, S., & McConachie, H.(2014). Systematic review of the properties of tools used to measure outcomes in anxiety intervention studies for children with autism spectrum disorders. *Plos ONE, 9*(1), doi:10.1371/journal.pone.0085268

Williamson, S., Craig, J., & Slinger, R.(2008).Exploring the relationship between measures of self-esteem and psychological adjustment among adolescents with Asperger syndrome. *Autism, 12,* 391-402.

Wing, L. and Potter, D.(2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews*, *8*, 151–161.

Wu, M., McGuire, J., Arnold, E. Lewin, A., Murphey, T. & Storch, E.(2013). Psychometric properties of the Children's Yale-Brown Obsessive Compulsive Scale in youth with autism spectrum disorders and obsessive-compulsive symptoms. *Child Psychiatry and Human Development, 45*(2), 201-211.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C.(2003). Prevalence of autism in a US metropolitan area. *Journal of the American Medical Association, 289*(1), 49–55.

Zvolensky, M., Kotov, R,. Antipova, A., & Schmidt, N.(2005). Diathesis stress model for panic-related distress: A test in a Russion epidemiological sample. *Behavior Research and Therapy, 43*(4), 521-532.

Appendix A: Consent Form

Study Title: Mother's Perceptions of Anxious Experiences in Children with ASD

Principal Investigator: Jessica Palilla, Graduate Student

Co-Investigator: Mikle South, Ph.D.

Introduction

You are invited to take part in a research study of how mothers perceive and understand their child's anxious behaviors, thoughts and emotions. We are trying to learn if there are qualitative differences between how anxious child experience anxiety and how children with ASD experience anxiety.

In order to decide whether or not you wish to be a part of this research study you should know enough about its risks and benefits to make an informed decision. This consent form gives you detailed information about the study, which a member of the research team will discuss with you. This discussion should go over all aspects of this research: its purpose, the procedures that will be performed, any risks of the procedures, and possible benefits. Once you understand the study, you will be asked if you wish to participate; if so, you will be asked to sign this form.

Procedures

This study has two parts. The first part includes taking several surveys online. The second part involves two interviews. Both parts of this study will be given in one meeting between you and the researcher and will take place at either the BYU Comprehensive Clinic or over the phone. Total time commitment will be between 120-150 minutes.

Part 1 includes filling out surveys about your child's development and anxious behavior and answering some basic questions about your demographic information. This will not involve your child directly. This should take between 30-45 minutes to complete. The demographic information, developmental questionnaire and anxiety questionnaire will be taken online.

Part 2 involves an interview. The interview will ask you questions about your child's anxious thoughts based on questionnaire that you completed online. The interview will require you to think of specific examples when your child was anxious and a set of questions in relation to each example. It should take 60-90 minutes to complete this interview. The interview with be audio recorded to ensure accuracy. Interviews over the phone will be recorded via an application on an iphone. Interviews given in person will be recorded using an application on a Macbook Pro computer.

Risks/Discomforts

Risks associated with this experiment are minimal. Filling out the surveys and answering interview questions may take mental effort. You may feel some discomfort when being audio recorded.

Benefits

This study may not provide any direct benefits to you. It is hoped that this study will contribute to the scientific community's understanding of how children with ASD experience anxiety. The information gathered from this study may result in improved interventions for ASD children and questionnaires that assess for anxiety in the ASD populations with greater accuracy.

Confidentiality

If you decide to be in this study, the researcher will get information that identifies you and your child and information about you and your child. This may include information that

might directly identify you, such as your name, age, and phone number. The principal

investigators will keep a link that identifies you to your coded information (via assigned number)

and this link will be kept secure and available only to the Principal Investigators or selected

members of the research team.   Any information that can identify you will remain confidential.

The principal investigators will only give this coded information to other members of the

research team to carry out this research study. Once completed, the audio recordings will be kept

on an encrypted drive. This information will be kept for seven years.   After that time it will be

destroyed or de-identified, meaning we will replace your identifying information with a code that

does not directly identify you.

In the future, direct quotes may be used in presentations or papers. Any quotes will not

contain any identifying information, and will only be linked to your assigned participant number.

Results from the surveys may be sent to an offsite facility. Data will include the age and gender

of your child, but no other identifying information. You may choose to not allow your survey

information to be sent offsite at any time.

Any identifiable information that is obtained in connection with this study will remain

confidential and will be disclosed only with your permission or as required by U.S. or State law.

Examples of information that we are legally required to disclose include abuse of a child or

elderly person, or certain reportable diseases.   Data are safeguarded in locked cabinets in locked

offices, and electronic data are stored on password-protected computers.   When the results of the

research are published or discussed in conferences, no information will be included that would

reveal your identity unless your specific consent for this activity is obtained.

Representatives from the BYU Institutional Review Board (the Committee that reviews, approves, and monitors human subject research) may inspect study records during auditing procedures.   However, these individuals are required to keep all information confidential.

<u>Compensation</u>

You will receive a $45 Amazon gift card following the completion of the surveys and the interviews. Compensation not be prorated.

<u>Participation</u>

Participation in this research study is voluntary. You have the right to withdraw at anytime or refuse to participate entirely without jeopardy to your relationship with Brigham Young University or to the Principal Investigator.   Withdrawal from this study will not affect your ability to receive treatment in the Comprehensive Clinics or any other BYU entity.   You are free to choose not to take part in this study and if you do become a participant you are free to stop and withdraw from this study at any time during its course.   To withdraw, you can call a member of the research team at any time and tell them that you no longer want to take part. The researchers may withdraw you from participating in the research if necessary, such as when the difficulty associated with testing is judged to be harmful or if you are not complying with research procedures.

<u>Questions about the Research</u>

We have used some technical terms in this form.   Please feel free to ask about anything you don't understand and to consider this research and the consent form carefully – as long as you feel is necessary – before you make a decision. You may contact the principal investigator and/or co-investigator at any time at this address: Jessica Palilla, Graduate Student & Mikle

South, Ph.D., 245 Taylor Building, Brigham Young University, Provo, Utah, 84602.   Phone

(801) 422-4058, email jm.palilla@gmail.com.

Questions about your Rights as a Research Participant

If you have questions regarding your rights as a research participant contact IRB

Administrator at (801) 422-1461; A-285 ASB, Brigham Young University, Provo, UT 84602;

irb@byu.edu.

Signatures

I have read (or someone has read to me) this form and have decided to participate in the

project described above.   Its general purposes, the particulars of involvement and possible

hazards and inconveniences have been explained to my satisfaction.   My signature also indicates

that I have received a copy of this consent form.

Name of Participant: _____

Signature: _____

Date: _____

_____   _____

Signature of Person Obtaining Consent   Date/Time

Appendix B: SCAS Parent Interview

Introduction

I am interested in finding out about your child's anxious thoughts. The word "anxious" is often used interchangeably with words like worried, nervous, scared, frightened, fearful and apprehensive, and is associated with certain types of thoughts, feelings, actions and bodily sensations.

I am going to ask you some questions about your child's anxious thoughts based on the questionnaire you have completed. I will be asking you to think of specific examples of times when your child was anxious, then I will ask you a set of questions in relation to each example. We will try to run through the set of questions quickly, so that we can get as full a picture as possible of your child's anxiety across different situations.

Part 1 Statements that you've indicated do apply to your child (ask further questions on maximum 4 statements that have been endorsed as "always" or "often"):

> You indicated that this statement describes your child:
>
> (e.g. My child worries about things)
>
> Can you give me an example of a time when your son/daughter was:
>
> (e.g. worried about things) ?
>
> Is that unusual, or fairly representative of the problem?
>
> **Proceed to ask below questions (E1 – E2; A1 – A5; P1 – P2; T1 – T3; C1 – C5; I1 – I2) in relation to each statement.**

Proceed to ask below questions (E1 – E2; A1 – A5; P1 – P2; T1 – T3; C1 – C5; I1 – I2) in relation to each statement to which the respondent replies 'yes' in question P1.

Emotions

E1.   How do you think your child felt in that situation?

E2.   How distressing do you think these feelings were for your child?

0	1	2	3	4
Not at all	Slightly	Fairly	Very	
Extremely		distressing	distressing	
distressing	distressing	distressing		

Actions

A1.   What did your child do in that situation that made you think your child was anxious?

A2.   What was it about what your child did in that situation that made you think that your

child was anxious?

A3-A5: used a prompt to help parents remember (may edit it to fit each situation)

A3.   Did your child do anything to **<u>avoid</u>** that situation? (If yes, please describe)

Or…   Did your child do anything to **<u>avoid previous/subsequent</u>** similar situations? (If yes,

please describe)

A4.   Did your child do anything to **<u>reduce/manage/prevent</u>** his distress in this situation? (If

yes, please describe)

Or…   Did your child do anything to **<u>reduce/manage/prevent</u>** his distress in

<u>previous/subsequent</u> similar situations? (If yes, please describe)

If yes to A3 or A4, ask A5 below.

A5.   What happened when your child was **<u>prevented</u>** from engaging in actions to reduce/manage/prevent these distressing feelings in this situation?

Or…   What **<u>would have happened</u>** if your child was prevented from engaging in these actions to reduce/manage/prevent these distressing feelings?

Physiological arousal

P1.   Do you think these feelings brought about any uncomfortable bodily sensations in your child?

See card for prompt –list of physical symptoms to jog memory

P2.   How uncomfortable do you think these bodily sensations were for your child?

0	1	2	3	4
Not at all uncomfortable	Slightly uncomfortable	Fairly uncomfortable	Very uncomfortable	Extremely uncomfortable

Thoughts

T1.   What thoughts do you think went through your child's mind in that situation?

This is the most complicated section: hard to come up with thoughts (feelings and emotions most often used) take very slowing and carefully (oh that sounds like a feeling—what do you really think is at the root of their anxiety in this situation)

T2.   How keen do you think your child was for these thoughts to go away?

0	1	2	3	4
Not at all keen	Slightly keen	Fairly keen	Very keen	Extremely keen

T3.   To what extent do you think these thoughts were reasonable given your child's

circumstances? (or to what extent were salience of thoughts reasonable?)

0	1	2	3	4
Not at all	Slightly	Fairly	Very	Totally
reasonable`	reasonable	reasonable	reasonable	reasonable

If respond 1, 2, 3 or 4…ask T4:

T4.   What was it about your child's circumstances that made you think his/her thoughts were

reasonable?

Aetiology/cause

C1.   Has this (state problem – e.g. *worrying about what other people think of him/her*) always

been a problem for your child?

C2.   If not, can you pinpoint when this problem began to emerge?

C3.   What was happening around that time (i.e. anything that parent believes explains

emergence of fear)?

C4.   Has this (state problem – e.g. *worrying about what other people think of him/her*)

changed over time?

0	1	2	3	4
Not changed	Slightly	Fairly	Very	Extremely
over time	changed over	changed over	changed over	changed over
	time	time	time	time

C5.   If yes, in what way has this problem changed over time?

Interference

I1.   How much does this problem interfere with your child's life?

0	1	2	3	4
Not at all interfering	Slightly interfering	Fairly interfering	Very interfering	Totally interfering

I2.   Unless 0 is endorsed… in what way does this problem interfere with your child's life?

I3.   How much does this problem interfere with family life?

0	1	2	3	4
Not at all interfering	Slightly interfering	Fairly interfering	Very interfering	Totally interfering

I4.   Unless 0 is endorsed…in what way does this problem interfere with family life?

Final questions

At the end of the interview (after questions have been asked about each of the statements), ask questions F1 – F3.

F1.   Is there anything that I haven't asked about your child's anxiety that you think is important/relevant?

F2.   Do you have any other comments about any of the questions I have asked today?

F3.   That is the end of all my questions.   Thanks you for taking the time to help with this research.   Would you be interested in receiving a short report at the end of the study that summarizes the findings from this research?

yes/no