

GROWING UP WITH AUTISM: EXPERIENCES OF ADULTS ON THE SPECTRUM
AND ASSOCIATIONS WITH DEPRESSION

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ABSTRACT

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The purpose of this study was to investigate the lived experiences of adults with an Autism Spectrum Disorder (ASD) and factors potentially associated with symptoms of depression. While depression is a commonly occurring comorbid disorder for individuals with ASD, the current body of research attempting to identify specific factors associated with depression is relatively limited. A mixed methods design was utilized, and both quantitative and qualitative analyses were conducted. Specifically the study attempted to identify whether perceived quality of parental relationships, gender, past involvement in extracurricular activities, number of friends, and involvement in past counseling services predict symptoms of depression among adults with ASD. One hundred and twenty six adults with ASD completed a survey questionnaire regarding their lived experiences, ASD, and symptoms of depression. One-way ANOVAs were conducted to examine potential relationships between depression and perceived quality of parental relationship, gender, past involvement in extracurricular activities and past involvement in counseling services. Additionally, a multiple regression was utilized to determine whether or not number of friends was associated with depression. Finally, thematic analysis was used to identify emergent themes. The results demonstrated perceived quality of parent

relationship and past involvement in extracurricular activities predicted symptoms of depression, although gender, number of friends, and past involvement in counseling services did not have a predictive relationship with symptoms of depression. The themes that emerged included both positive and negative aspects of emotional experiences, interpersonal relations, isolation, sensory experiences, and having a unique perspective. These results inform school psychologists of factors that may impact the development of depressive symptoms among individuals with ASD.

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CHAPTER I

INTRODUCTION

The diagnosis of Autism Spectrum Disorder (ASD) is based upon the observed presence of specific core features including deficits in social-emotional function, communication, and interpersonal relationships, as well as identifiable areas of restricted interest, or stereotypical and repetitive behaviors (American Psychiatric Association [APA], 2013). As the label implies, the diagnosis encompasses an incredibly wide range of individuals with unique characteristics and varying needs, some of whom also exhibit characteristics of comorbid psychological disorders (APA, 2013). This study sought to examine the associations between symptoms of depression and the lived experiences of adults who had previously been diagnosed with ASD. The results of this study add to the limited body of research regarding the identification of depression among individuals with ASD.

Autism Spectrum Disorder

History of Autism

Leo Kanner, an Austrian psychiatrist, was the first to identify and study classic autism (Blacher & Christensen, 2011). In 1943, Kanner presented the world with the term, early infantile autism. Kanner's work provided differentiation between ASD and what was previously considered to be psychosis or schizophrenia in children (Blacher & Christensen, 2011). Initially, autism was treated exclusively within the world of

psychiatry until the 1950s when Bruno Bettelheim and several of his colleagues began to intellectualize autism through Freudian notions. As noted by Silverman and Brosco (2007), Bettelheim and his peers suggested that autism was a result of parental rejection that led to ego damage, and behaviors associated with autism were a result of said ego damage. In 1964, Bernard Rimland suggested that infantile autism had a neurological basis and was highly associated with genetics (Silverman & Brosco, 2007).

Viennese pediatrician Hans Asperger first coined the term Autistic Psychopathy, which later became known as Asperger's syndrome, based on his observations of children he treated between 1950 and 1986 (Hippler & Klicpera, 2003). As noted by his case records, Asperger saw mostly young boys, who demonstrated comparable patterns of strengths and weaknesses. Asperger felt that Autistic Psychopathy was in some way connected to Kanner's report of autism (Hippler & Klicpera, 2003). Although Asperger did identify commonalities among the children he observed, he did not determine diagnostic criteria (Blacher & Christensen, 2011). When Lorna Wing published a clinical description of Autistic Psychopathy in 1981, she presented the term Asperger's syndrome (Wing, 1981), at which time Asperger's original work became widely known (Wolff, 2004). Wing (1981) expanded on Asperger's behavioral observations and further explored the developmental history of his case studies, identifying specific common characteristics. According to Wolff (2004), Wing focused on the observed difficulties the children exhibited in social interaction, emotional expression and processing, intuition, attention, and the distinct intellectual functioning originally described by Asperger. Wing also identified that the children Asperger observed did not demonstrate interest or

enjoyment in their primary relationships (Hippler & Klicpera, 2003). Wing offered the view that autism was a spectrum disorder, which always included deficits in social function, communication, and imagination (Hippler & Klicpera, 2003).

Etiology of Autism

As noted by Schaefer and Mendelsohn (2013), it is now known that ASD is a neurodevelopmental disorder with a genetic basis. Although it is widely acknowledged that genetics play a role in the development of ASD, the phenotype is extremely varied from individual to individual. Additionally, the presence of chromosomal abnormalities is commonly identified in individuals with ASD who undergo genetic testing (Schaefer & Mendelsohn, 2013). Correia, Café, Almeida, Mouga, and Oliveira (2014) noted that ASD may be a result of deviances in the expression or function of specific synaptic proteins. An alteration in the protein would likely impact either the structure or function of the synapse, and subsequently this may impair an individual's brain by not changing in response to experiences. Ultimately this proposed dysfunction at the synaptic protein level would lead to impairments in the connection of synapses, thus resulting in overall network functioning that would manifest as developmental delays and the failure to attain and utilize new skills related to social or communication function (Correia et al., 2014).

Prevalence Rates of Autism

According to the most recent data gathered in 2010 by the Center for Disease Control's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network, 1 in 68 children within the United States have an ASD (Baio, 2014). The ADDM conducted a national examination of children with an ASD who reside in one of the

eleven studied sites to determine specific and current prevalence rates. The ADDM's results indicated that the prevalence varied based on gender and ethnicity. It was noted that the prevalence of ASDs among males was consistently much higher than among females with ratios ranging from three to one and five to one. Additionally, it was determined that, when comparing the national sites, prevalence rates were greatest for white children, followed by black children and lastly Hispanic children (Baio, 2014).

Previous research has demonstrated that males are four times more likely to be diagnosed with an ASD when compared to females (Russell, Steer, & Golding, 2011). The higher representation of males with a diagnosis of ASD is attributed, in part, to gender biases and stereotyping among evaluators. Russell et al. (2011) found that despite the severity of presenting ASD symptoms, females are less likely to receive a diagnosis than males. In other words, even in instances where females display equally severe symptoms, males are more likely to receive a diagnosis. Additionally, Attwood (2006) suggested that females may be less likely to be identified as having an ASD because they are more likely to watch and imitate their more socially competent peers, thus concealing their social skills deficits. Based on this information, it can be concluded that there exist a greater number of females with an ASD who are never identified, and therefore are not adequately represented in research samples (Russell et al., 2010).

Diagnostic Criteria for Autism Spectrum Disorder

The *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5; APA, 2013), currently defines the diagnosis of an ASD by characteristic deficits in the domains of social-emotional functioning, communication, and the development and

maintenance of interpersonal relationships. The current diagnostic criteria for ASD also include the presence of restricted interests and repetitive and stereotypical behaviors. These characteristic features, while exhibited to some degree by all individuals diagnosed with an ASD, will undoubtedly vary in severity and presentation (APA, 2013). The previous edition of the manual, DSM-IV (APA, 2000), differentiated ASDs and included the separate diagnoses of Asperger Syndrome (AS) and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) in addition to the diagnosis of Autism. The most recent classification of ASD, as defined by the DSM-5, incorporates the aforementioned diagnoses into one category differentiated by severity of symptoms (Mazzone et al., 2013). Currently, all previous diagnoses fall under the category, Autism Spectrum Disorder, and is distinguished by three levels of severity, based upon the degree of support each individual requires in regards to communication and patterns of restricted, repetitive behaviors (APA, 2013).

Depression

History of Depression Diagnosis

Knaus and Ellis (2012) maintain that depression has been referenced within some of the earliest found written or illustrated accounts of history. It has been suggested that evidence of depression has been discovered within the earliest hieroglyphics and paintings of ancient Egypt, at which time depression was not stigmatized and treatments included sleep, expeditions, and dance. Further, Hippocrates studied depression among individuals of ancient Greece. He speculated that individuals were born with a predisposition to develop depression, which could be triggered by stressful events, and

that one's emotional response would effect the trajectory of their depressive symptoms. He determined that a healthy diet and movement were appropriate treatments for depression (Knaus & Ellis, 2012). Lawlor (2012) explored the historical accounts of depression in his book, *From Melancholia to Prozac*. He noted that depression was initially known as melancholia, and the term depression appeared sometime during the 18th century. Early accounts of depression focused on experiences of debilitating sadness and anxiety (Lawlor, 2012). It was thought for a period of time that those who experienced depression were of superior intellectual ability, particularly during the Renaissance period (Lawlor, 2012).

As noted by Richards (2011), the conceptualization of the general nature and course of depressive disorders has evolved fairly dramatically in the past twenty years. Depressive disorders were previously thought to be either organic (a disease of the brain), or reactive in nature. Depressive disorders that were considered to be organic were thought to be associated with a more negative prognosis and to be chronic. Those considered to be reactive were thought to have a more positive trajectory and to be curable often once the cause was removed (Richards, 2011).

Etiology of Depression

Aaron Beck, American psychoanalyst and psychiatrist, like Hippocrates, determined that depression is the result of a combination of factors, which likely include a genetic vulnerability paired with a triggering life event or situation (Knaus & Ellis, 2012). More specifically, depression has been associated with the occurrence of a chemical imbalance such as serotonin inefficiency within the brain (Knaus & Ellis,

2012). Further, Essau, Lewinsohn, Seeley, and Sasagawa (2010) asserted that previous research has determined that depression, specifically Major Depressive Disorder (MDD), within the general population has been associated with not only various biological factors, but also social and psychological factors. For instance, rates of MDD among females have been associated with hormonal fluctuations, instances of physical and sexual abuse, frequent rumination, childhood adversity, and experiencing a number of interpersonal stressors simultaneously (Essau et al., 2010).

Prevalence Rates of Depression

As noted by Pratt and Brody (2008), the CDC released the findings of the National Health and Nutrition Examination Survey based on data collected during 2005 and 2006, and determined that among individuals over the age of 12, 5.4% reported experiencing depression. The rates were higher among those that were between 40 and 59 years of age, women, and non-Hispanic black individuals as compared to other surveyed demographic groups. The CDC also reported that socioeconomic status was an associated factor as higher rates of depression were reported among those of lower socioeconomic status, as defined by living below the current federal poverty level (Pratt & Brody, 2008). Additionally, the CDC reported that among those individuals surveyed between 2007 and 2010, 8% of all individuals over the age of 12 reported experiencing depression at the time that information was gathered. The CDC also indicated that among those same individuals, females reported depression more than males in all age groups that were surveyed (Pratt & Brody, 2014).

Diagnostic Criteria for Depression

According to the DSM-5 (APA, 2013), characteristic features of all depressive disorders include the presence of an unhappy, vacant, or irritable mood state experienced in conjunction with somatic and intellectual changes that significantly adversely affect an individual's ability to function in daily life. Depressive disorders are marked by similar symptomatology, but are differentiated by the length, timing, or assumed etiology of the episodes (APA, 2013).

According to Magnuson and Constantino (2012), the World Health Organization has identified depression as the primary public health burden within the United States and the third largest public health burden in the world. Depression has been identified as a major public health concern in part as a result of its' chronic, reoccurring nature as well as the impact depression has on physical health, general ability to function, and the heightened risk of suicide by individuals suffering from depression (Magnuson & Constantino, 2012).

Within the general population, it has been established that MDD is more frequently diagnosed among females when compared to males (Essau et al., 2010). These gender differences are present in both adolescents and adults, and previous research suggests that the diagnostic sex differences emerge during adolescence, specifically the period of time between the ages of 15 and 18. Research has also demonstrated that gender is associated with lifetime outcomes of individuals diagnosed with MDD. Females diagnosed with MDD typically experience a greater number of depressive episodes, as well as lengthier episodes of depression (Essau et al., 2010).

Historical Accounts of Depression among Individuals with Autism

Historically, symptoms of depression have been documented in individuals with ASD. Both Kanner and Asperger made note of symptomatology consistent with depression among the individuals with ASD that they respectively studied. Asperger stated, “clinically diagnosable anxiety and varying rates of depression...seem to be related to a painful awareness of handicap and difference from other people” (Meyer, Mundy, Van Hecke, & Durocher, 2006, p. 384). However, it has been only recently that researchers have made a concerted effort to focus on the experiences of depression among those diagnosed with an ASD (Rosbrook & Whittingham, 2010).

In addition to Kanner and Asperger, Lorna Wing’s (1981) work yielded observations that anxiety and depression were common among individuals diagnosed with autism (Barnhill, 2007). She, like Asperger, hypothesized that the presence of clinical anxiety and depression in adolescents and adults with autism may be associated with an increased awareness of being different. Further, she noted that adult outcome appeared to be mediated by individual characteristics such as level of functioning, ability, and temperament (Barnhill, 2007).

Importance of the Study

This study will add to the scarce amount of research focused on the understanding of depression among individuals with ASD. Research regarding the conceptualization of individuals with ASD is imperative because, while depression is common within this population, relatively little research has been conducted (Stewart, Barnard, Pearson, Hasan, & O’Brien, 2006). Understanding the presentation and associated factors of

depression among individuals with ASD is critical as those individuals with ASD who do experience depression also experience overall relatively poorer quality of life (Strang et al., 2013). Specifically, the data collected will provide additional information used for conceptualizing a variety of factors that may be associated with depression or depressive symptoms among adults with ASD. The information gained through the information collected will aid in the development of specific profiles associated with vulnerability or contributing factors to the development of depression within individuals with ASD. Therefore, the findings of the proposed study may guide future identification of factors associated with the developmental of depression.

Research Questions

The specific research questions that will be explored are:

1. Does perceived quality (positive, negative, or neutral) of parental relationships predict the presence of symptoms of depression?
2. Does gender predict the presence of symptoms of depression?
3. Does past involvement in extracurricular activities predict the presence of symptoms of depression?
4. Does number of friends predict the presence of symptoms of depression?
5. Does involvement in past counseling services predict the presence of symptoms of depression?
6. Do themes emerge from the free response items that are associated with the presence of symptoms of depression?

CHAPTER II

LITERATURE REVIEW

While research regarding ASD is rapidly emerging, few of the available studies focus on individuals with ASD and the development of depression or depressive symptomatology. The purpose of this chapter is to explore the available research regarding individuals with ASD who are also suffering from depression. Specifically, the presentation of depression in individuals with ASD will be explored, with focus on similarities and distinctions between those with ASD and the general population. Additionally, the known information regarding the etiology of depression in individuals with ASD will be explored, as well as protective and risk factors in the development of depression. Finally, this chapter will examine the current methods of assessment for identifying depression in individuals with ASD.

High Functioning Autism Spectrum Disorder

Prior to the most recent publication of the DSM-5 (APA, 2013), the descriptor High Functioning Autism Spectrum Disorder (HFASD) emerged from the literature, and has been utilized as an inclusive term for individuals who previously met diagnostic criteria for either AS or PDD-NOS, as well as those individuals diagnosed with ASD who also demonstrate average to above average intelligence, despite significant overlap between characteristic features (Volker et al., 2009). There has been some debate regarding the existence of a distinction between AS and HFASD, but ultimately the

similarities prove to be more significant than any distinction between the two diagnoses (Mazzone et al., 2013). Both individuals with AS and HFASD exhibit specific social communication challenges such as excessive use of formal speech, difficulty in reciprocal conversation, and the use of atypical prosody. Additionally, it appears as though any distinctions between AS and HFASD, such as delayed early language development in individuals with HFASD and a higher mean total and verbal IQ seen in many individuals with AS, become less apparent over time. Once into adulthood, both those formally diagnosed with AS or considered to have HFASD demonstrate very similar cognitive and behavioral profiles (Mazzone et al., 2013). Generally, individuals diagnosed with HFASD, AS, or PDD-NOS exhibit relative strengths in language and cognitive ability despite pragmatic language deficits (Volker et al., 2009). For example, as noted by Colle, Baron-Cohen, Wheelwright, and van der Lely (2007) individuals with HFASD and AS do not exhibit the same marked language deficits as typically seen among individuals with classic Autism, but still exhibit challenges in regards to communicating within a social context. In alignment with both the current definition of ASD as outlined in the DSM-5 (APA, 2013) as well as the findings of previous research, ASD will be the term utilized throughout this paper and will include individuals who may previously have been considered to meet diagnostic criteria for ASD, AS, or PDD-NOS.

Presentation of Depression in Individuals with ASD

Presentation among the General Population

Within the general population, symptoms of depression vary depending on unique individual characteristics such as developmental maturation, gender, and age. While

there are core commonalities in the manifestation of depression, symptoms present differently across an individual's developmental trajectory and maturation (Magnuson & Constantino, 2012). For instance, it has been determined that sadness and irritability are the most reliable predictors of depression among preschool aged children. Among preschool aged children who were determined to have depression, the majority suffered from anhedonia, or the lack of enjoyment experienced during typically pleasing activities. As children mature, they may exhibit symptoms of depression through somatic complaints and externalizing behaviors. Additionally, themes of death or suicide may be present during play or other activities. During adolescence, hypersomnia and an increased risk of suicide often accompany the core features of depression (Magnuson & Constantino, 2012). As noted by Essau et al. (2010), during adolescence and puberty gender differences begin to emerge with nearly twice as many adolescent females with depression as compared to adolescent males. The increase in the gender differences in prevalence is likely in part due to socialization, hormonal factors, and stressful events specific to adolescence (Essau et al., 2010). As the developmental trajectory advances into adulthood, Hegeman, Kok, van der Mast, and Giltay (2012) noted that late life depression is associated with increased agitation, somatization (general and gastrointestinal), and the tendency to act as a hypochondriac.

It has been established that prevalence rates are not the only distinguishing factor between females and males with depression. Among the general population, females with depression are more likely to exhibit changes in appetite and weight, cry more frequently, and experience feelings of guilt or low self-worth. On the other hand, males with

depression typically indicate experiencing anhedonia, withdrawal from socializing, and fluctuations in energy or mood (Magnuson & Constantino, 2012). Generally speaking, females exhibit a more chronic outcome when diagnosed with depression and typically experience longer depressive episodes when compared to males (Essau et al., 2010).

While females are more likely to experience chronic and severe depression, males with depression are at a much higher risk of attempting suicide when compared to females. As noted by Rice, Fallon, Aucote, and Moller-Leimkuhler (2013) males with depression are four times more likely to die by suicide when compared to females. Additionally, males are more likely to engage in substance use or exhibit maladaptive externalizing behaviors when confronted with negative emotional states (Rice et al., 2013).

Presentation of Depression in Individuals with ASD

According to Magnuson and Constantino (2012), the presence of depressive symptomatology has a significant impact on the functionality of individuals with ASD; unfortunately, identification of depression in the context of a comorbid ASD diagnosis can be challenging. To further complicate the matter of identification, the presentation of depressive symptoms fluctuates based on a variety of unique individual factors (Magnuson & Constantino, 2012). Due to some of the core features of ASD, the presentation of depression in individuals with an ASD may vary widely. For instance, due to challenges related to communication, individuals with ASD may have difficulty expressing subjective mood states and deficits in theory of mind further negatively impact an individual's ability to engage in self-reflection (Magnuson & Constantino, 2012).

Additionally, as noted by Ghaziuddin, Ghaziuddin, and Greden (2002), as a result of deficits related to affect and cognition, individuals with autism may not accurately represent their internal emotional state with an appropriate corresponding facial expression, making it difficult for those around them to accurately identify mood states. Further, individuals with ASD display impairments in communication and therefore may not be able to express subjective states of unhappiness, hopelessness, or indifference accurately (Magnuson & Constantino, 2012).

As noted by Magnuson and Constantino (2012), as is common among the general population, themes of death have been reported in individuals with ASD during periods of depression. Children with ASD who have been identified as also suffering from depression may exhibit an increase in self-injurious behaviors such as head banging or self-hitting. Affective changes are common among individuals with ASD, including an increase in aggression, irritability, and agitation, with rapidly changing mood states. Interestingly, both increases and decreases in ASD symptomatology have been reported in individuals with depression. Characteristics of ASD that typically increase include ritualistic or obsessive behaviors, which are often accompanied by an increase in irritability and hyperactivity. Although reported less frequently, some individuals with ASD exhibit a loss of interest in repetitive behaviors and preoccupations, greater social withdrawal, and a marked decrease in adaptive function (Magnuson & Constantino, 2012).

Gotham, Unruh, and Lord (2014) determined that many of the symptoms present among the general population suffering from depression are also present for those with HFASD and depression. The authors conducted a study in which 50 individuals ranging in age from 16 to 31, who were diagnosed with HFASD, completed self-report measures of depressive symptoms. The authors evaluated their responses and any associations present as they related to individual participant characteristics. In addition to those symptoms commonly observed among the general population, Gotham et al. (2014) noted that individuals with HFASD who are exhibiting symptoms of depression may experience a shift in their preoccupations or areas of interest, focusing on more morbid interests, as well as an increase in compulsive behaviors. Additionally, the researchers noted that among the most frequently endorsed items among the participants of their study were items that were associated with negative attributions regarding self and circumstances, or the cognitive symptoms of depression (Gotham, et al., 2014).

Griffith, Totsika, Nash, and Hastings (2012) conducted a qualitative analysis of the lived experiences of several individuals with ASD. The authors conducted semi-structured interviews with 11 participants ranging in age from 37 to 57 years. Four themes emerged from the research questions. The themes that emerged were as follows: difficulties in living with ASD, employment challenges, negative experiences with mainstream supports, and future plans to support others with ASD. The researchers found that individuals with ASD perceived neurotypical individuals as having a much easier time navigating through life than they were. The participants generally reported that they were aware that others may perceive them as being “odd,” which may aggravate

their feelings of depression. Overall, the participants of the study indicated that they felt as though inadequate services and support were due to a lack of understanding from the neurotypical individuals who provided services. The participants indicated that they felt it was the lack of understanding and knowledge that should be addressed in order to facilitate provision of effective supports (Griffith et al., 2012).

Etiology of Depression in Individuals with ASD

The etiology of depression in individuals with ASD is multifaceted. Depression may occur in this population due to genetic or environmental factors, or the interplay of both (Ghaziuddin et al., 2002). As noted by Rieffe, De Bruine, Rooij, and Stockmann (2014), while the prevalence rates of depression among individuals with ASD are high, the etiology of depression in this population has yet to be thoroughly examined. The authors conducted a study to determine whether or not emotional dysregulation, which is an established contributor to depression among the general population, is associated with depression in individuals with ASD and depression. The researchers focused on three aspects of emotional regulation: approach, avoidance, and rumination, and whether or not there was a relationship between any of the three examined aspects and depression in children (aged 9-15) with ASD. The authors compared the group of children with ASD to a group of children who were determined to be of typical development. Both groups completed self-report measures at three points in time with a period of nine months between each point of data collection. The results of the study indicated that approach and avoidance strategies were negatively associated with depression in both studied groups, while higher rumination was positively associated with depression. Additionally,

the children with ASD reported higher depressive symptomatology and less use of approach strategies when compared to the group of control children. Overall, the researchers found that emotional dysregulation, specifically rumination and the lack of approach strategies, was associated with depression among the children with ASD (Rieffe et al., 2014).

Gadow, Pinsonneault, Perlman, and Sadee (2014) conducted a related study in which they examined the emotional dysregulation of children with ASD and any existing relationship with the dysregulation of dopamine metabolism. The relationship between emotional dysregulation and dopamine metabolism dysregulation has been previously established within individuals with Attention-Deficit/Hyperactivity Disorder (ADHD). The authors included a sample of 110 children with ASD and compared their dopaminergic gene variations with parent and teacher ratings of emotional dysregulation and ADHD. The authors found that two specific dopamine transporter genes and a dopamine D2 receptor gene were significantly associated with depression. This information suggests that the dysfunction of dopaminergic genes may moderate depressive symptoms among children with ASD (Gadow et al., 2014).

As noted by Magnuson and Constantino (2012), the genetic association between individuals with ASD and depression is evident. Individuals with ASD who have been diagnosed with depression often have a significant family history of depression (Magnuson & Constantino, 2012). Hallett, Ronald, Rijdsdijk, and Happe (2010) conducted a study to look more closely at the familial connection and the development of internalizing traits in children with ASD. The researchers conducted a study of 6,000

pairs of twins born between 1994 and 1996 in England and Wales. The authors noted that the sample was comprised of children who represented the spectrum of ASD traits, and 1.8% of the participants met criteria for ASD as indicated by the Childhood Autism Spectrum Test (Scott, Baron-Cohen, Bolton, & Brayne, 2002). Parents provided information regarding characteristics of ASD and internalizing behaviors over the course of several years. Specifically, when the children were 7 and 8 years old, and later at 12 years old. The results of the study indicated that the presence of more severe characteristics of ASD early on was associated with the later development of internalizing behaviors. The authors also found that early communication difficulties were significantly related to the later development of internalizing traits. The authors noted that the most noteworthy communication difficulties manifested themselves within social situations. Additionally, the development or existence of internalizing behaviors may continue to further impede communication abilities. For instance, individuals who experience internalizing traits in early childhood may avoid opportunities that would foster the development of social communication. The authors found that the converse association is also true. Participants who experienced early difficulties in social interaction and communication were expected to later experience relatively greater anxiety and depression, likely as a result of avoiding social interactions, which in turn may impact the individual's ability to pursue support or express themselves (Hallett et al., 2012).

Prevalence Rates of Depression among Individuals with ASD

The reported prevalence rates of comorbid depression among individuals with autism vary greatly, ranging from 4 to 38 percent according to Stewart et al. (2006), and 1.5 to 10 percent according to Magnuson and Constantino (2012). Despite discrepancies among prevalence rates, it has been determined that depression is one of the most common comorbid psychiatric conditions individuals with ASD experience (Strang et al., 2012). As previously reported, the prevalence rates of depression among the general population obtained between 2007 and 2010 by the CDC were at 8% for individuals 12 and older (Pratt & Brody, 2014). Mazzone et al. (2013) conducted a study with the purpose of identifying the specific clinical phenotype of individuals with HFASD. The researchers organized the 95 participants into three groups: individuals with a diagnosis of HFASD, a second group of participants diagnosed with HFASD and MDD, and a third group with no diagnoses. The authors' results indicated that the subjects with HFASD exhibited greater depressive symptoms when compared to the subjects without MDD and HFASD, and no significant differences between depressive symptoms were found between the groups with HFASD and MDD (Mazzone et al., 2013). Additionally, the proportion of subjects with HFASD and MDD who reported depressive symptomatology above the mean was very similar, suggesting that individuals with HFASD experience low mood symptoms much more frequently than the general population (Mazzone et al., 2013).

According to Lai et al. (2011), there is no evidence to suggest that there are gender differences in the diagnosis of comorbid psychological disorders in individuals

with ASD. The authors sought to examine whether the increased number of females within the general population who report symptoms of depression when compared to males, also held true for males and females diagnosed with ASD. They conducted a study comprised of 62 participants, 33 males and 29 females, who met diagnostic criteria based upon the results of the Autism Diagnostic Interview-Revised (ADI-R). The participants ranged in age from 18 to 45, did not have an intellectual disability and had a previous clinical ASD diagnosis in addition to the information gained from the ADI-R. The researchers found that while a significant number of their sample, both male and female, reported clinically significant anxiety or depression symptomatology, no significant gender differences were found. Although, it is noteworthy to mention that 69% of the female sample reported depressive symptomatology, as compared to 54.5% of the male sample. The authors noted that while their research did not demonstrate any significance between males and females, they hypothesized this may have been due to not including associated physiological manifestations of depression, which may have produced different results. The authors suggested that in the future, the use of physiological measures related to comorbid psychiatric symptoms could potentially yield gender differences (Lai et al., 2011).

According to a study conducted by Mayes, Calhoun, Murray, and Zahid (2013) increasing age, IQ, and severity of ASD characteristics are associated with the development of depressive symptoms, while the converse, decreased age, lower IQ, and less severe ASD characteristics, as well as fewer social problems were considered to be protective factors against the development of symptoms of depression in individuals with

autism. The authors included a sample of 627 participants, who ranged in age from 1 to 17 years of age and met the DSM-IV-TR criteria for either AS or ASD. The authors set out to determine whether a relationship existed between maternal ratings of depression, and age, IQ, gender, race, parental occupation, ASD severity, and existing comorbid problems. The results indicated that depression was not significantly related to the participants' race, gender, or parent occupation, but correlations existed between severity of autism, somatization, negative mood states, and social problems. Additionally, the most significant predictors of depression were severity of ASD characteristics, verbal IQ, and age (Mayes et al., 2013).

As noted by Mazzone et al. (2013), research has provided mixed results regarding the correlation between IQ and depressive symptoms in individuals with HFASD. Several studies have provided evidence for the association, while others do not indicate a correlation. In conducting their own study examining the clinical presentation of comorbid psychological disorders among children and adolescents with HFASD, Mazzone et al. (2013) found that IQ was not predictive of depressive symptoms. But, the authors did find evidence to suggest that depression was associated with the presence of externalizing symptoms (Mazzone et al., 2013). Depression was found to be associated with maladaptive behaviors such as hyperactivity, self-injury, and aggression. Additionally, it was determined that as depressive symptoms increased among individuals with HFASD, overall global functioning was likely to be poorer as evidenced by a more impaired psychological profile and greater challenges in social adjustment (Mazzone et al., 2013).

Sterling, Dawson, Estes, and Greenson (2007) conducted a study of forty-six adults with ASD in order to determine the relationship between individual characteristics (severity of ASD symptoms, IQ, and comorbid psychiatric disorders) and the presence of depression. Not unlike aforementioned studies, it was determined that the participants who had fewer social impairments and higher IQs were more likely to indicate they were experiencing depression. The researchers also found that those participants who reported depression were more likely to exhibit symptoms of general anxiety and obsessive-compulsive disorder (OCD), which are all highly co-morbid among the general population as well (Sterling et al., 2007).

Risk and Protective Factors

Risk Factors

Characteristics of autism. As noted by Strang et al. (2012), symptoms of depression in individuals with ASD have been associated with relatively less severe characteristics of autism. Specifically, it has been determined that those individuals with ASD who exhibit more intact social functioning and social skills are more vulnerable to the development of depression (Sterling et al., 2007). It has also been suggested that individuals with ASD who are aware of their social challenges, are more susceptible to experiencing symptoms of depression (Strang et al., 2012). Individuals with ASD who recognize themselves as being different from their peers have increased depressive symptomatology (Magnuson & Constantino, 2012). As noted by Magnuson and Constantino (2012), those individuals with ASD who attributed their social difficulties to

their own deficiency of ability as opposed to external factors, experienced greater depressive symptoms.

Attribution style. Anecdotal aspects of previous research have suggested that individuals, who attribute social failure to their own challenges, are more likely to exhibit characteristics of learned helplessness. While learned helplessness has not been directly researched in the context of ASD and depression, it has been theorized that learned helplessness among individuals with ASD is an important risk factor in the development of depressive symptomatology (Magnuson & Constantino, 2012). Kanne, Christ, and Reiersen (2009) studied college students with characteristics of ASD and found that as associated ASD traits increased, so did external locus of control, further supporting the notion that learned helplessness may contribute to the development of depressive symptoms. Conversely, when success is perceived as an option, individuals demonstrated increased motivation and more appropriate social interaction (Kanne et al., 2009).

Consistent with studies conducted among the general population, specific patterns of social cognition and processing may be predictive of depressive symptomatology among individuals with ASD (Barnhill, 2001). Specifically, individuals with ASD who engage in a negative attribution style are at greater risk for the development of depression (Barnhill, 2001). Barnhill (2001) found that adolescents with HFASD who attributed their social challenges to their own social abilities or lack thereof (as opposed to chance, effort, or the difficulty of a given task) were more likely to experience symptoms of depression.

Meyer et al. (2006) provided similar results when they examined the relationship between specific processing patterns of social information and their relationship to comorbid psychological disorders. The authors found that those individuals with HFASD who were able to engage in self-reflections regarding their social anxiety, competency in social interaction, and their difficulty in developing interpersonal relationships, fared comparatively less well than less insightful peers. These individuals were not only more aware of their limitations, but were also sensitive to teasing and rejection, were more likely to engage in negative self-evaluation, and were more likely to experience loneliness (Meyer et al., 2006).

Co-morbid disorders. It has been hypothesized that co-morbidity of psychopathology has a cumulative effect leading to more severe impairments and greater likelihood of additional psychopathology (Gadow, Guttman-Steinmetz, Rieffe, & DeVincent, 2012). The co-morbid diagnosis of ADHD in individuals with ASD may be a risk factor for the development of depression, as the co-occurrence of ADHD is likely to exacerbate social deficits. In 2006, Gadow, DeVincent, and Pomeroy conducted a study and found that male and female children diagnosed with both ASD and ADHD were more likely to exhibit symptoms and behaviors associated with more severe global depression ratings. More recently, Gadow et al. (2012) substantiated the aforementioned findings by conducting a study with a sample of 478 school-aged males. The researchers designated participants to one of five groups based on diagnosis, a group of boys with ASD and ADHD, a group of boys with chronic multiple tic disorder (CMTD), a group of boys with ADHD, a group of boys with ASD, and finally, a control group of boys who

did not have a diagnosis. The authors examined relationships between each group and depressive symptoms, and found that their caregivers and educators reported the highest levels of depressive symptomatology among the group of boys with both ASD and ADHD (Gadow et al., 2012).

Developmental level. Maturation and development appear to be associated with the potential development of depressive symptoms and depression. It is known that depression symptoms increase from childhood into adolescence within the general population, and this has also been demonstrated in individuals with HFASD (Vickerstaff, Heriot, Wong, Lopes, & Dossetor, 2007). Specifically, for individuals with ASD, depressive symptoms and depression are most likely to occur in adolescence and adulthood (Sterling et al., 2007).

Anger. Quek, Sottronoff, Sheffield, White, and Kelly (2012) found that individuals diagnosed with HFASD experienced clinically significant levels of anger when compared to the general population. Additionally, it was found that anger was a statistically significant predictor for depression among those that participated in the study. Therefore, individuals with HFASD who present emotional and behavioral characteristics of anger may be more likely to develop symptoms of depression (Quek et al., 2012).

Protective Factors

Perceived social support. Concerning resiliency, previous research studies have identified the presence of strong social support networks as a protective factor against the development of depressive symptomatology within the general population (Flynn,

Kecmanovic, & Alloy, 2010). Lasgaard, Nielson, Eriksen, and Goosens (2009) conducted a study focused on adolescents with ASD and loneliness, which has been associated with mental health concerns. The researchers included a sample comprised of 39 boys with ASD and a control group of 199 boys who did not have a diagnosis of ASD. The participants all completed the UCLA Loneliness Scale (third version) (Russell, 1996) as well as the Social Support Scale for Children (Harter, 1985). The researchers found that having a diagnosis of ASD was significantly associated with often or always experiencing loneliness, but that perceived social supports were negatively associated with loneliness in the subjects with ASD. Specifically, the subjects with ASD who had parental support and two or more typically developing siblings reported significantly less loneliness. Additionally, perceived social support from peers was negatively associated with loneliness, indicating familial and peer support are protective factors against experiences that may lead to depression (Lasgaard et al., 2009).

Assessing Depression in Individuals with ASD

Diagnostic Criteria

The current definition and criteria of depressive disorders are outlined by the DSM-5 (APA, 2013). It was determined that there exist no apparent significant differences between chronic MDD and what was previously known as dysthymia, so the two have been combined with specifiers. Generally speaking, in order to meet diagnostic criteria for MDD, an individual would have to exhibit a depressed mood or a loss of concern or enjoyment in day-to-day activities for a period of time longer than two weeks. The aforementioned depressed mood must be identified as a departure from the

individual's base line mood and their function in some capacity, social, occupational, or education must also be impaired. When the depressed mood becomes chronic (i.e., lasting for at least two years in adults), the individual may be diagnosed with Persistent Depressive Disorder (APA, 2013).

In addition to meeting the previously noted criteria, the individual must also exhibit a majority of the following behaviors regularly: depressed mood or irritation, loss of interest or enjoyment, a change in weight or appetite, a change in sleep patterns, a loss in overall energy or exhaustion, feelings of guiltiness or worthlessness, difficulty in concentration, or thoughts of death or suicidal ideation. Depression and depressive symptomatology occurs on a continuum from mild to severe (APA, 2013). The most recent publication of the DSM-5 has identified that it is possible for individuals with unipolar depression to exhibit what are considered manic features and has emphasized the importance of the presence of anxiety among individuals with depression (APA, 2013).

As a result of characteristic communication deficits, diagnosis of depression in individuals with ASD is commonly based upon the observation of externalizing behaviors or changes in mental states observed by caregivers (Magnuson & Constantino, 2012). Previous research has identified that caregivers of individuals with ASD and co-morbid depression consistently report observable behaviors related to states of sadness or hopelessness, such as increased tearfulness, sadness, apathy, and increased negative affect. Caregivers also report observing anhedonia, sleep and weight changes, fluctuations in performance and skills, as well as catatonic behavior (Magnuson & Constantino, 2012).

Cooper and Hanstock (2009) advise researchers and assessors to acknowledge the characteristics of ASD that overlap with depression, but may not necessarily indicate the presence of depression. Observable characteristics such as blunted affect, monotone speech, limited emotional facial expressions, and social isolation alone do not indicate symptoms of depression (Cooper & Hanstock, 2009). Additional overlapping symptoms include sleep and appetite disturbances. These symptoms are chronic among individuals with ASD while individuals who suffer from depression as their sole diagnosis experience these symptoms episodically. Therefore, when identifying and diagnosing depression in individuals with ASD, a critical factor is whether or not there has been a marked impairment in an individual's level of functioning (Cooper & Hanstock, 2009).

According to Magnuson and Constantino (2012), when clinicians are considering a diagnosis of depression for an individual with ASD, it is incredibly advantageous to consider any change in baseline behavior, including changes in behaviors characteristic of ASD. Several studies have also provided evidence for the significance and accuracy of utilizing self-report measures with individuals with HFASD, suggesting that individuals with HFASD may have more insight than previously thought regarding their own thought patterns and emotional states, particularly when presented with information in the form of questionnaire (Gotham et al., 2014; Ozsivadijian, Hibberd, & Hollocks, 2013).

Summary

Individuals with ASD are widely researched and studied, although research focused on individuals with ASD and depression is currently an area of need. Prevalence rates of depression among individuals with ASD have been reported as 1.5 to 10 percent (Magnuson & Constantino 2012) to 4 to 38 percent (Stewart et al., 2006) as compared to the reported prevalence of 8 percent within the general population (Pratt & Brody, 2008). Research demonstrates many similarities between the presentation of depression among the general population and individuals with ASD who also have depression, as well as differences. Due to characteristics of ASD, individuals on the spectrum may experience difficulty expressing subjective mood states (Magnuson & Constantino, 2012) and may not accurately represent internal states with corresponding facial expressions (Ghaziuddin et al., 2002). Additionally, individuals with ASD who are exhibiting symptoms of depression may exhibit a change in their preoccupations or areas of interest, focusing on more morbid interests, as well as an increase in compulsive behaviors (Gotham et al., 2014).

The development of depression among individuals with ASD is likely due to a combination of genetic and environmental factors (Ghaziuddin, et al., 2002). Although, the etiology of depression in individuals with ASD has yet to be comprehensively evaluated (Rieffe et al., 2014), the development of depression is likely due to such factors as emotional dysregulation (Rieffe et al., 2014), dopamine dysregulation (Gadow et al., 2014) and genetic associations (Magnuson & Constantino, 2012). Risk factors for the development of symptoms of depression among individuals with ASD include social and

communication related challenges. Specifically, risk factors regarding social communication include the awareness of those difficulties (Strang et al., 2012), external locus of control (Magnuson & Constantino, 2012), specific patterns of social cognition and processing (Barnhill, 2001), as well as co-morbid psychopathology (Gadow et al., 2012). Social support networks have been identified as a protective factor against the development of depression (Flynn et al., 2010).

Continued research specific to individuals with ASD and depression is critical and despite depression commonly occurring, relatively little research has been conducted (Stewart et al., 2006). The presence of depression in individuals with ASD is related to overall relatively poorer quality of life, and therefore justifies the need to understand the lived experiences of those who experience depressive symptoms (Strang et al., 2013). The information gained from this study will contribute to the literature by providing specific and unique experiences associated with depressive symptoms, as well as further information regarding protective and risk factors.

CHAPTER III

METHODOLOGY

The purpose of this exploratory study was to investigate the potential relationship between various factors and reported symptoms of depression among adults who have previously been diagnosed with ASD. Specifically, the researcher was interested in identifying factors associated with the presence of depressive symptomatology in order to guide future intervention and provide appropriate supports to individuals with ASD who exhibit symptoms of depression.

The data examined was culled from archival data gathered during 2012-2014. Data was collected through the use of an online survey created and posted by a research team at a university in northern Texas. This study was approved by the university's Institutional Review Board.

Study Design

The study design utilized was a mixed method approach. As noted by Hanson, Creswell, Clark, Petska, and Creswell (2005) the mixed method approach within psychology allows for enriched results due to the ability to generalize results as well as achieve a greater understanding of the studied phenomenon. While the mixed method approach includes obstacles, for instance it is very time intensive, it has emerged as a viable alternative to strictly qualitative or quantitative research (Hanson et al., 2005). Further, mixed methods are beneficial in that their use generates not only answers to

research questions, but also facilitates the generation of important future research (Johnson, Onwuegbuzie, & Turner, 2007). The use of mixed methods was warranted, as it was likely to yield superior and richer information due to the nature of the research questions and study. The data that was analyzed in this study was obtained from an online survey of adults with ASD. Item responses were used to address questions about diagnosis, social relationships, and symptoms of depression. As this is was an exploratory study, research questions were used instead of directional hypotheses.

Participants

The participants included 126 individuals who self-identified as adults (age 18 and older) with a previous diagnosis of ASD. When conducting an ANOVA, a minimum of 30 participants per cell is considered a reasonable sample size, and should provide power at 80%, which is the minimum power for an ordinary study (VanVoorhis & Morgan, 2007). A 2010 study examining the relationships between experiences of bullying and social supports through the use of thematic analysis yielded a sample size of 36 (Humphrey & Symes, 2010), thus indicating sufficient power for the qualitative portion of the study. Participants were limited to individuals who were willing and able to complete an online survey and were able to do so at a location of their choice.

Procedures

The survey was available online only. A message about the study was posted to websites that adults with ASD would likely frequent, such as blogs, support groups, and other specific online communities. The message contained a hyperlink that connected the individual to the survey, which was hosted by www.psychdata.com. The survey was

encrypted using Secure Sockets Layering (SSL) to protect the confidentiality of the participants. The first screen of the survey was a consent form explaining the purpose of the study and the risks involved in participation. At the end of the consent form, the participant was given the option of agreeing to participate. If “Agree” was selected, the participant began the survey and if the participant indicated that they did not agree, they were navigated away from the survey. The survey was expected to take approximately 45 minutes to complete.

Instrumentation

Participants completed a 61-item questionnaire that was developed by members of the research team. This researcher utilized a select number of items from the survey when conducting the analysis. The survey asked for demographic information as well as posed questions specific to living with ASD. Several survey items addressed aspects related to when the participant first learned they had autism, which type of ASD diagnosis they initially received, if they had ever been diagnosed with depression in the past, their perception of their diagnosis, whether or not the participant had ever received counseling or mental health services, and what type of services, if any, the participant received during school.

The survey also included questions that asked for information regarding the individual’s perceptions of their relationships with family members and peers. For instance, if they had siblings, participants were asked to describe their relationship, identify how old they were when they realized they were different from their sibling, and identify whether or not they felt close to their sibling. Participants were also asked to

identify and elaborate on their general perceptions of interpersonal interactions. For example, participants are asked whether or not they feel others understand them, or whether or not others listen to them. The survey also contains items related to perspectives of having an ASD diagnosis. For instance, participants are asked to identify the best thing about growing up with autism, the most difficult thing about growing up with autism, identify what advice they might have for others with autism, and identify what autism means to them. The survey also contained items relevant to symptoms of depression. Items intended to measure symptoms of depression were created based upon the diagnostic criteria and symptoms listed in the DSM-IV-TR (APA, 2000) and are consistent with symptoms listed in the DSM-5 (APA, 2013). See Appendix for survey items. Survey items were presented in a variety of formats, including yes/no questions, limited free response items, several varieties of multiple-choice items, and scaled items. Although the items were presented in a variety of formats, this is not uncommon. For instance, the Child Behavior Checklist (CBCL) (Achenbach, 1991), a checklist that has been proven valid and reliable in detecting concerns regarding emotional and behavioral function in children, presented with items in a variety of formats (Dutra, Campbell, & Westen, 2004). Because the research team created the questionnaire, there is no current information regarding its reliability and validity. However reliability was analyzed.

Research Design

The researcher elected to create exploratory questions as opposed to directional hypotheses in order to avoid looking at only one end of the distribution and to allow for more possibility. As noted by Fields (2009), making a specific prediction of direction

does allow significance to be found with greater power, although if the prediction is made in the wrong direction, significance will be over looked. Additionally, in behavioral research it is difficult to justify assuming an outcome will occur in only one direction, which is why the majority of behavioral research utilizes two-tailed tests (Punch, 2013). In order to add to the existing body of research regarding individuals with ASD and their experiences of depression, the researcher developed the following exploratory questions:

1. Does perceived quality of parent relationships predict the presence of symptoms of depression?
2. Does gender predict the presence of symptoms of depression?
3. Does past involvement in extracurricular activities predict the presence of symptoms of depression?
4. Does number of friends predict the presence of symptoms of depression?
5. Does involvement in past counseling services predict the presence of symptoms of depression?
6. Do themes emerge from the free response items that are associated with the presence of symptoms of depression?

Statistical Analysis

Quantitative analysis. The researcher utilized the Statistical Package for Social Sciences (SPSS, 2011) software in order to analyze the gathered quantitative data. Prior to analyzing the data, statistical assumptions were checked. Descriptive statistics were obtained for all quantitative variables. In order to address the proposed research questions, several analyses were conducted.

The dependent variable utilized in each of the quantitative analyses, the depression mean, was developed by creating a composite score in SPSS (2011). The composite score was comprised of survey items intended to gain a measure of severity of depression symptoms based upon the diagnostic criteria outline within the DSM-IV-TR (APA, 2000). Respondents were asked to identify how often they experienced pleasure in activities typically enjoyed, changes in appetite, changes in sleep patterns, fatigue or loss of energy, difficulty concentrating, difficulty making decisions, negative thoughts about themselves or their abilities, and hopelessness about the future. Each item was presented with a Likert scale style response, which allowed the participants to indicate the frequency that they had experienced each symptom on a weekly basis. Based upon his or her responses, an average score was generated for each individual participant.

With the first question (does perceived quality of parental relationships predict the presence of symptoms of depression?), a one-way analysis of variance (ANOVA) was used to determine if significant differences in the presence of depression, the dependent variable, existed based on individual perception (positive, negative, or neutral) of parent relationships, the independent variable. An ANOVA is used when examining the relationship between one continuous dependent variable and one categorical independent variable with two or more levels (Meyers, Gamst, & Guarino, 2006).

For the second question (does gender predict the presence of symptoms of depression?), an ANOVA was also utilized to determine whether gender, the independent variable, predicted the presence of depressive symptoms, the dependent variable.

An ANOVA was used to address the third question (does past involvement in extracurricular activities predict the presence of symptoms of depression?). The outcome of the ANOVA identified whether or not having participated in extracurricular activities, the independent variable, in the past predicted the presence of symptoms of depression, the dependent variable.

Multiple regression was used to address the fourth question (does number of friends predict the presence of symptoms of depression?). The regression was utilized to determine whether perceived number of friends, the independent variable, was statistically significantly related to the presence of depressive symptoms, the dependent variable. Regression was selected because the independent variable, number of friends, is a continuous variable. Finally, an ANOVA was used to answer the fifth question (does involvement in past counseling services predict the presence of symptoms of depression?). The ANOVA was utilized to determine whether or not having received counseling services in the past, the independent variable, was predictive of the presence of depressive symptoms, the dependent variable.

Qualitative analysis. Thematic analysis was also used as an analytic strategy in order to closely examine free response items as they relate to depression. Thematic analysis has been utilized previously in a study examining the self-report of individuals who identified as HFASD and their description of emotional experiences (Jones, Zahl, & Huws, 2001). Additionally, Humphrey and Symes (2010) utilized thematic analysis in order to examine the role and impact of social supports for individuals with ASD who experienced bullying.

The thematic analysis guidelines set forth by Braun and Clarke (2006) were employed as the framework for analyzing qualitative information. Specifically, thematic analysis allowed the researcher to recognize, investigate, and report any themes that emerged as they related to symptoms of depression in individuals with ASD. As indicated by Braun and Clarke (2006), thematic analysis was selected over other existing qualitative analytic methods for its flexibility, as well as its utility and accessibility for researchers who are new to the world of qualitative analysis (Braun & Clarke, 2006). Braun and Clarke (2013) have asserted that thematic analysis is simply a method of analysis, as opposed to more complex quantitative methods, which could be identified as methodology. Because thematic analysis is independent of existing theoretical frameworks, it can be learned and utilized without the knowledge necessary for other qualitative approaches (Braun & Clarke, 2013).

According to Braun and Clarke (2006), a theme can be identified as a pattern of responding or meaning inside the data. In alignment with Braun and Clarke's (2006) recommended guidelines, the free response items were carefully read and, based upon the content, coding structures were identified. Codes were then sorted based upon how they came together to comprise overarching themes. The themes were then reviewed in order to eliminate groupings that were not actual themes, which were redefined by identifying any themes that could fold into one another. Another doctoral level psychology graduate student was recruited to code the same responses utilizing the provided code lists. The graduate student verified this process, and coding was compared. The researchers discussed differences in coding in order to arrive at a consensus.

CHAPTER IV

RESULTS

The purpose of this chapter is to provide the results of both the quantitative and qualitative research questions and analyses. The descriptive statistics are provided followed by the primary analyses of each quantitative question. Themes that emerged from the thematic analysis of the qualitative items are then provided.

Quantitative Results

Preliminary Analysis

A total of 126 participants provided demographic information. Descriptive statistics for participant information are included in Table 1. The participants were fairly evenly divided between males and females, although eight individuals listed other genders. The majority of participants (N = 108) reported being white or Caucasian, two participants reported their ethnicity as black or African American, one individual reported their ethnicity as biracial, one individual indicated that they were Native American, and 14 participants indicated ethnicity information that was categorized as other.

Respondents ranged in age from 18 to 67. The majority of participants (N = 75) were within the young adult age range (i.e., 18-29 years), 25 participants reported their age as between 30 and 39, 24 participants indicated that they were middle aged (i.e., between 40 and 64), and 2 participants reported that they were 65 or older. Most participants (N = 105), reported that they were diagnosed with Asperger's syndrome

while the remaining participants reported being diagnosed with other classifications of autism.

Table 1.

Sample Demographic Frequencies and Percentages

Demographic Variables	Frequency (<i>N</i> = 126)	Percentages
Gender		
Female	60	47.6%
Male	58	46.0%
Transgender	3	2.4%
Genderqueer	2	1.6%
None	3	2.4%
Race/Ethnicity		
White/Caucasian	108	85.7%
Black/African American	2	1.6%
Biracial	1	.08%
Native American	1	.08%
Other	14	11.0%
Age		
Young Adulthood (18-29)	75	59.5 %
Thirties (30-39)	25	19.8 %
Middle Age (40-64)	24	19.0 %

Table 1 Continued

Demographic Variables	Frequency (<i>N</i> = 126)	Percentages
Age		
Aged (65 & older)	2	1.5%
Diagnosis		
PDD NOS	3	2.4%
Autism	6	4.8%
Asperger Syndrome	105	83.3%
Other	10	7.9%
Missing	2	1.6%

Depression Mean Composite

The survey items intended to measure symptoms of depression were based upon the diagnostic criteria and symptoms listed in the DSM-IV-TR (APA, 2000). Those items were used to create a composite score, referred to as the depression mean, which was used as the dependent variable in each quantitative analysis. Specifically, the depression mean was comprised of eight survey items, and one of which was reversed coded prior to creating the composite due to a variation in phrasing. The eight survey items prompted participants to rate their experiences of pleasure for activities typically enjoyed, ability to make decisions, experiences of hopelessness, negative thoughts about themselves or their abilities, feelings of fatigue, ability to concentrate, changes in appetite, and any changes in sleep behavior on a weekly basis. Frequency statistics and

percentages for the depression mean composite, and each individual item can be found in Table 2. In order to gain a measure of the depression mean composite reliability, Cronbach's Alpha (Cronbach, 1951) was calculated ($\alpha = .751$), and was determined to be acceptable (Meyers et al., 2006). The descriptive statistics for the depression mean composite item analysis are provided in Table 3.

Table 2.

Depression Mean Composite Items Frequencies and Percentages

Composite Item	Frequency (<i>N</i> =126)	Percentage
How often do you find yourself focusing on activities you usually enjoy?		
Never	67	53.2%
1 day or less each week	38	30.2%
2-3 days each week	11	8.7%
Almost everyday	4	3.2%
Missing	6	4.8
How often do you find yourself having difficulty making decisions?		
Never	11	9.2%
1 day or less each week	25	19.8%
2-3 days each week	41	32.5%

Table 2 Continued

Composite Item	Frequency (<i>N</i> = 126)	Percentage
Almost everyday	42	33.3%
Missing	7	5.6%
How often do you find yourself feeling hopeless about the future?		
Never	4	3.2%
1 day or less each week	32	25.4%
2-3 days each week	39	31.0%
Almost everyday	44	34.9%
Missing	7	5.6%
How often do you find yourself having negative thoughts about yourself or your abilities?		
Never	4	3.2%
1 day or less each week	32	25.4%
2-3 days each week	39	31.0%
Almost everyday	30	23.8%
Missing	7	5.6%
How often do you find yourself feeling tired or fatigued?		
Never	5	4.0%

Table 2 Continued

Composite Item	Frequency (<i>N</i> = 126)	Percentage
1 day or less each week	16	12.7%
2-3 days each week	36	28.6%
Almost everyday	64	50.8%
Missing	5	4.0%
How often do you find yourself having difficulty concentrating?		
Never	12	9.5%
1 day or less each week	17	13.5%
2-3 days each week	32	25.4%
Almost everyday	60	47.6%
Missing	5	4.0%
How often do you find yourself eating more or less than usual?		
Never	15	11.9%
1 day or less each week	27	21.4%
2-3 days each week	47	37.3%
Almost everyday	34	27.0%
Missing	3	2.4%

Table 2 Continued

Composite Item	Frequency	Percentage
(N=126)		
How often do you find yourself sleeping more or less than usual?		
Never	7	5.6%
1 day or less each week	26	20.6%
2-3 days each week	38	30.2%
Almost everyday	51	40.5%
Missing	4	3.2%

Table 3.

Descriptive Statistics for Depression Mean Composite Reliability

	Cronbach's	Standardized Item	N = Items		
	Alpha	Alpha			
Reliability Coefficients	.751	.741	8		

	Mean	Minimum	Maximum	Range	Variance
Item Means	2.819	1.584	3.327	1.743	.298
Item Variances	.871	.584	1.101	.516	.031
Inter-Item Correlations	.263	-.025	.651	.676	.025

Research Question One

A one-way ANOVA was conducted in order to identify whether a significant relationship existed between the independent variable, perception of relationship with parent(s), and the dependent variable, depression mean. Because this survey item was presented in an open-ended response format, individual participant responses were coded prior to running the statistical analysis. The researcher coded the responses into one of four categories, positive, neutral, negative, or cannot be coded, creating a categorical independent variable with four levels. The fourth category, items that could not be coded, was created for unclear or complex responses that included conflicting descriptions of perception of parental relationship. Descriptive statistics for the ANOVA can be found in Table 4.

The results of the ANOVA (Table 5) suggested a significant mean difference was found between two groups ($F(4, 119) = 5.678, p < .05, \eta^2 = .16$). Bonferroni multiple comparison tests ($p < .05$) indicated that participants who reported having a positive perception of their relationship with their parents ($M = 2.64, SE = .08$) had significantly lower depression means than participants who described their perception of parent relationships as negative ($M = 3.10, SE = .10$).

Table 4.

Descriptive Statistics for ANOVA: Perception of Parental Relationship

Group	<i>N</i>	Mean	<i>SD</i>
Positive	43	2.64	.55
Neutral	13	2.79	.73
Negative	35	3.10	.44
Other	29	2.70	.57

Table 5.

One-way ANOVA: Perception of Parental Relationship and Depression Mean

	<i>Df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Between groups	4	6.769	1.692	5.678	.000*
Within groups	119	35.465	.298		
Total	123	42.27			

*Significant at the .05 levels

Research Question Two

A one-way ANOVA was utilized to determine the existence of any relationship between the independent variable, gender, and the dependent variable, depression mean. Gender was presented on the survey in an open-ended response format allowing participants to self-identify. Prior to analysis, gender responses were initially coded in five categories, female, male, transgender, genderqueer, and not specified. Descriptive statistics can be found in Table 6.

Table 6.

Descriptive Statistics for ANOVA: Gender and Depression Mean

Group	<i>N</i>	Mean	<i>SD</i>
Female	57	2.82	.57
Male	59	2.81	.59
Other			
Transgender	3	3.00	.82
Genderqueer	2	3.25	1.06
Not specified	3	2.67	.71

The results of the ANOVA (Table 7) indicated that no significant difference existed between the participants' gender and depression mean ($F(4, 119) = .378, p = .82$). The researcher then conducted another ANOVA examining gender and depression mean, after combining the categories of transgender, genderqueer, and not specified into one group representing gender minorities, due to their comparatively small sample sizes. The second gender ANOVA (Table 8) revealed no significant differences among gender and depression mean ($F(2, 121) = .148, p = .861$).

Table 7.

One-way ANOVA: Gender and Depression Mean

	<i>Df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Between groups	4	.530	.132	.378	.824
Within groups	119	41.704	.350		
Total	123				

Table 8.

One-way ANOVA: Gender and Depression Mean

	<i>Df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Between groups	2	.103	.051	.148	.86
Within groups	121	42.131	.0348		
Total	123				

Finally, a third gender ANOVA (Table 9) was conducted comparing only male and female participants. Although the first two gender analyses did not yield significant results, the third gender ANOVA was run because gender differences among individuals suffering from depression is observed within the general population. The third ANOVA did not indicate any significant mean differences among gender when the categories representing male and female were isolated and compared against only one another ($F(1, 114) = .003, p = .959$).

Table 9.

One-way ANOVA: Gender and Depression Mean

	<i>Df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Between groups	1	.001	.001	.003	.959
Within groups	114	38.225	.335		
Total	115				

Research Question Three

A one-way ANOVA was conducted in order to identify any potential relationships between participants' past involvement in extracurricular activities and their depression mean. Descriptive statistics for the ANOVA can be found in Table 10. The ANOVA (Table 11) indicated that significant mean differences existed ($F(1, 121) = 4.085, p = .045$). Specifically, those individuals who indicated they participated in extracurricular activities while growing up ($M = 2.745, SE = .064$) also reported significantly lower depression means as compared to individuals who did not participate in extracurricular activities while growing up ($M = 2.966, SE = .089$).

Table 10.

Descriptive Statistics for ANOVA: Extracurricular Activities and Depression Mean

Group	<i>N</i>	Mean	<i>SD</i>
Yes	81	2.75	.56
No	42	2.97	.60

Table 11.

One-way ANOVA: Extracurricular Activities and Depression Mean

	<i>Df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>P</i>
Between groups	1	1.351	1.351	4.085	.045*
Within groups	121	40.026	.331		
Total	122	41.378			

*Significant at the .05 levels

Research Question Four

Multiple regression was utilized to examine potential relationships between the participants' reported number of friends and depression. The multiple regression (Table 12) indicated no significant differences between participants' number of friends and depression means ($F(1, 120) = 1.31, p = .225$).

Table 12.

Multiple Regression Number of Friends and Depression Mean

	<i>B</i>	<i>SE B</i>	β
Number of Friends	-.139	.122	-.104
R^2		.105	
F		1.31	

Research Question Five

A one-way ANOVA was utilized in order to determine the existence of any relationships between involvement in past counseling services and participants' depression mean. Descriptive statistics for this ANOVA can be found in Table 13. The ANOVA (Table 14) revealed no significant differences between participants' involvement in counseling services and depression means ($F(1, 49) = 1.375, p = .247$). Notably, this particular item has fewer responses as compared to the previous analyses, as it was added to the survey as part of an addendum after the original survey had been available online for some time.

Table 13.

Descriptive Statistics for ANOVA: Counseling Services and Depression Mean

Group	<i>N</i>	Mean	<i>SD</i>
Yes	47	2.992	.57425
No	4	2.625	.91856

Table 14.

One-way ANOVA: Counseling Services and Depression Mean

	<i>Df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Between groups	1	.497	.497	1.375	.247
Within groups	49	17.700	.361		
Total	50				

Qualitative Results

The individual responses to several open ended survey items were analyzed in order to identify any potential themes that emerged. The open-ended items analyzed prompted participants to identify the best thing about growing up with ASD and the most difficult thing about growing up with ASD. All qualitative information was analyzed in the same manner. Prior to any attempt at formal coding, the researcher became familiar with the data by thoroughly reading the provided responses. While reading, the researcher noted possible commonalities across responses. As indicated by Braun and Clarke (2006), coding is dynamic and occurs throughout the analytic process. After reading through the data, initial codes were generated by the researcher and then refined. The responses were analyzed based on a semantic approach. More specifically, the researcher examined responses based on their explicit meanings, then summarized and interpreted the information looking for implications and overall meanings (Braun & Clarke, 2006). At this point in the process, another doctoral level psychology graduate student recruited by the researcher also utilized the Braun and Clarke (2006) model to independently code the responses. The researcher and graduate student reviewed codes, discussed any differences that existed and came to an agreement for each differing code. That information was then sorted into broader themes by the researcher. After generating themes, the researcher reviewed and refined the themes in order to determine if there was enough support for a given theme, or if multiple themes could be collapsed into one.

The Best Thing about Growing Up with Autism

When asked to identify the best thing about growing up with ASD, 119 participants provided responses. The researcher became familiar with the text, and then created and subsequently refined a list of codes (Table 15) representing all provided responses. Another doctoral level psychology student cross-coded the responses, which were then compared to the researcher's final codes.

The Most Challenging Aspect of Growing Up with Autism

When asked to identify the most challenging aspect regarding growing up with ASD, 121 participants responded. As with the subsequent question, the researcher first became well versed with the text, then created and refined a list of codes (Table 16) for each provided response. The responses were cross-coded by another doctoral level psychology student, which were compared to the researcher's codes.

Table 15.

Codes for the Best Things about Growing Up with Autism

Ability to utilize problem solving, logic and/or rationality	Acquire new skills quickly
Intelligence	Family relationships
Ability to discern patterns	Emotional detachment
Enjoy time alone	Rich inner life
Strong memory	Creativity
Engaging with others who have ASD	Specific skills

Table 15 Continued

Specific area of interest	Sensory experiences (pleasure)
Ability to focus	Acceptance
Knowledge of ASD characteristics	Independence

Table 16

Codes for the Most Difficult Things about Growing Up with Autism

Social isolation	Unable to understand most other people
Rejection	Feeling different
Misunderstood by others	Late diagnosis
Coordination challenges	Sensory experiences (negative)
Communication challenges	Social skills/social understanding/social awareness challenges
Emotional regulation difficulties	Bullied
Punished for being different	Specific interests (different from others)
Dependence on others	Anxiety
Obsessive thought patterns	Loneliness

Themes

The codes from both responses were used to form themes, which were then defined, and relationships among themes were then explored. The final themes include emotional experiences, interpersonal relations, isolation, sensory experiences, and having

a unique perspective. Each theme is reflected by both negative and positive aspects, or ways in which respondents described each theme as either advantageous or as a challenge to be overcome in relation to living with a diagnosis of ASD. In the following sections, participants' quotes are used to illustrate the themes. Unless otherwise noted, the participants are self-reported as being white/Caucasian with a diagnosis of Asperger's Disorder.

Emotional experiences. Emotional experiences were comprised of the codes representing responses that described both positive and negative aspects of emotional responses, including emotional detachment and emotional dysregulation. Individuals who responded with examples of emotional detachment identified the ability to emotionally detach as an asset in a variety of situations. For example, several individuals described emotionally detached experiences as positive and advantageous. A 19-year-old male stated, "I like being able to see the world differently from others. Many social issues that are hotly debated (such as gun control) are easy for me to see past the emotional aspects and simply delve into the logical standpoints. I also find it easy to simply 'ignore' peer pressure at certain times." Another participant noted an additional example of emotional experiences described as a positive attribute in the form of emotional detachment. A 30-year-old male explained, "The best thing in my autism is that I have the ability to generally remain calm in a crisis or emergency, due to an innate ability to detach myself emotionally from situations."

Other participants described emotional experiences as a challenge to be overcome, and identified this characteristic as one of the negative aspects of living with

ASD. For example, a 39-year-old male noted, “Emotional regulation is greatly lacking, as I get overwhelmed quickly.” He specifically noted having difficulty “properly expressing empathy especially towards my ailing mom.” A 24-year-old female explained that she is “Unable to express, identify, or understand emotions correctly.” She noted that because of her inability to accurately perceive and express emotion, she began “incorrectly expressing them outwardly as a result (smiling when sad/uncomfortable/stressed, laughing when hurt or when inappropriate, crying when confused/angry, people unable to understand outbursts/breakdowns/ meltdowns).” A 25-year-old female stated, “I frequently had very strong negative emotions and did not know how to express them appropriately. I am still in the process of learning healthy communication.”

Interpersonal relationships. Interpersonal relationships is a theme defined by a multitude of aspects and contributing factors that either facilitate or inhibit quality social interaction. The positive aspects individuals reported included positive familial relationships and connecting with others who have ASD. The challenging codes that comprise this particular theme include a lack of social awareness, communication challenges, and experiences of bullying. Responses representing positive aspects of this particular theme included enriched interpersonal relations.

For example, a 30-year-old female explained, “Since I had few friends, growing up with autism meant I grew very close to my sister, and sometimes even her friends, even though we were 3.5 years apart in age and 4 grades apart in school. We shared a lot of interests (orchestra, board games, TV shows, both avid readers) and so I always had

somebody to talk to if I wanted.” A 20-year-old male diagnosed with Autism, stated that he benefited from “Joining a program in which I met people with similar issues (Autism, Asperger’s, etcetera). I was able to make friendships free from the sense of judgment that came with my primary school experience. Long-term friendships came from this program.”

Responses representing the challenging aspects of interpersonal relationships describe barriers to the development of quality connections with others including bullying, a lack of social awareness, and communication difficulties. A 30-year-old female described being bullied while growing up and stated, “I was bullied in school, particularly in middle and high school, largely because I was an easy target because of my autism. Teachers just told me to ‘ignore them,’ but that did not work well, since they particularly liked to ask me questions, which I automatically answer truthfully. My hygiene was at a lower standard than they liked, so they'd ask me how often I showered, for instance. I could not remember to lie or not answer – I was asked a question, so I gave the answer.”

A 22-year-old female noted that she experienced difficulty “Learning social norms. I was always confused by actions of relatives and schoolmates.” Further, a 49-year-old female stated that she experienced interpersonal relationship challenges as she felt she was “Being bullied and the butt of jokes. Not being able to understand or comprehend things that other people take for granted. The anger. People’s cruelty and ignorance.”

Isolation. Isolation is also a theme defined by both its positive and negative attributes. Many participants identified they felt fortunate to enjoy the presence of their own company, while others reflected on moments in their lives when they felt lonely and alienated due to isolation that wasn't necessarily chosen. Respondents who described social isolation as a positive aspect of ASD, described situations in which they were able to spend time alone engaging in creative endeavors or engaging in activities that reflected a rich inner life. A 23-year-old individual stated, "I honestly really liked being able to tune out everything. I spent one summer where each day, every day, I would spend roughly twelve hours in the pool with no one else there. My mom would bring me lunch but I wouldn't get out or talk to anyone. It was very peaceful, and nice. I could spend a long time in my head with fictional worlds, and get a lot of joy out of that where other people would be really bored." A 25-year-old Polish male stated, "I think differently and am rarely bored. I have a very active imagination and can get lost in my own thoughts for hours. I also rarely feel lonely and can do productive things rather than have to fill a social need by being with friends."

Other respondents described social isolation in a more negative light – as something they had not chosen and as a source of difficulty for them. Respondents who described social isolation as alienation also reported feeling lonely as a result of the lack of connection. For example, a 49-year-old female stated she experienced isolation as "Being rejected for reasons beyond your comprehension; you simply don't know or understand why. Being alone." Additionally, a 35-year-old female described challenges

that she faced, “Being a social outcast. Fearing social situations and wanting to be involved at the same time. Feeling like I stick out in a crowd and everyone dislikes me.”

Sensory experiences. Sensory experiences also emerged as a theme, with both positive and negative connotations. In regards to the positive aspects, participants identified the pleasure they derived from heightened sensitivity to sensory experiences. A 21-year-old Irish male stated that he experienced, “Heightened senses. I feel like I can pick out very specific sounds in music, and tastes in food that other people can’t appreciate.” Further, a 22-year-old female diagnosed with PDD NOS explained that she benefitted from enjoyable sensory experiences, and stated “A lot of things also bring me joy. Spinning on tire swings, pleasing music, Christmas lights, I Spy books; they all made me so happy despite all the emotional distress. Sensory sensitivity works both ways.”

Other participants reflected on experiences when their acute awareness of sensations went unnoticed by those around them, became a distraction, and at times, impaired their ability to function within a particular environment. A 32-year-old female discussed her hypersensitivity and stated, “I have a lot of anxiety about things I can't control, and sensory overload is torture.” A 26-year-old female stated, “I didn't like wearing clothes, especially jeans, shoes, and socks. It was awful how hot my feet would get and how much it felt like my freedom of movement was restricted by my clothing. I had no way to explain why I hated them so much, so tantrums were the norm. The worst part was not knowing how to filter stimuli, and not knowing how to communicate

sensory overload. There was a lot of anger, frustration, crying, screaming, and hiding in small spaces because of it.”

Unique perspectives. Additionally, unique perspective emerged as a theme with several sub themes including intelligence, academic success, specific skill sets, ability to acquire new information quickly, a strong memory for detail, and viewing the world in patterns. A 24-year-old male explained something he liked about himself was his perspective, and stated, “I like the way I analyze things and being ‘more logical’ than a lot of people I meet. I feel like I think a lot faster than a good chunk of the people I encounter.” A 39-year-old male stated he enjoys “The fact that I see the world almost entirely in patterns, numbers, shapes. I also think in pictures and can remember the slightest detail. I am drawn to classical music and can really enjoy its complexity, especially during an aria. Having a long-term special interest has led to my career interest.”

Other participants described being challenged by their unique perspective because it resulted in their being misunderstood by others, and to their misunderstanding most other people. A 26-year-old female described her experience of “Getting stuck on specific things. I would get a word in my head and have to say it constantly. Another thing was tapping my fingers together, as a kid I had to constantly do it. I got made fun of A LOT for my repetitive motions and words. I also got made fun of for how much I liked some things and saying the wrong thing. Mostly I am happy with myself, its how others perceive me that is the issue.” A 25-year-old male articulated both the positive and challenging aspects of being able to perceive the world differently. He explained

that he appreciates “The mental agility whenever I need to think about something. Being able to focus on the minute details whilst being able to focus on the big picture at the same time, it's a positive but also a negative because the people around me rarely can keep up with my mind and thought processes, even to this day.”

Summary

The quantitative analysis indicated that a significant relationship existed between the participants' perception of relationship with parent(s) and the dependent variable, depression mean. Specifically, those individuals who described their relationship with their parent(s) as positive had significantly lower depression means. Significance was observed at the .05 level. Additionally, the analyses examining the relationship between past involvement in extracurricular activities and the depression mean was also significant at the .05 level. Individuals who reported participating in extracurricular activities had lower depression means. The other variables examined through quantitative analysis, gender, past involvement in counseling services, and number of friends, did not yield any significant relationships. The qualitative analysis resulted in five themes, each defined by both positive and negative aspects. The thematic analysis provided emotional experiences, interpersonal relationships, isolation, sensory experiences, and having a unique perspective as either a challenge to be overcome or an asset of having ASD.

CHAPTER V

DISCUSSION

The present study sought to examine the lived experiences of adults with ASD, and factors potentially associated with symptoms of depression. A mixed methods design was utilized to examine the presence of depressive symptoms and any potential relationships between specific factors. Quantitative analysis was employed in order to identify any significant relationships between depression and participants' perception of their parental relationships, gender, number of friends, participation in extracurricular activities, and participation in counseling services. Qualitative analysis was utilized to explore the information provided by two open-ended response items. Specifically, the researcher utilized a method of thematic analysis developed by Braun and Clarke (2006) in order to identify themes that arose based on participants' descriptions of the best and most challenging aspects of having an ASD diagnosis.

Summary of Findings

Quantitative Analysis

The first research question, which examined any potential relationship between the participants' perception of their parental relationships and depressive symptoms, yielded statistically significant results. Specifically, participants who reported their perception of their parental relationships to be positive also reported significantly lower symptoms of depression as compared to participants who indicated their perception of

parent relationships to be negative. Previous research has demonstrated that individuals with ASD demonstrate the ability to develop meaningful and quality attachments with their parents. Rutgers, Bakermans-Kranenburg, Ijzendoorn, and Berckelaer-Onnes (2004) conducted a meta analysis of studies regarding attachment patterns and styles of children with ASD. It was found that less secure attachment was observed among some children with ASD when compared to non-clinical samples, but these differences disappeared for samples of children with ASD who exhibited relatively higher cognitive abilities and comparatively less severe characteristics of ASD (Rutgers et al., 2004). Rutgers et al.'s (2004) findings suggest that individuals with high functioning ASD, such as the participants of this study, develop parental attachment no differently than non-clinical individuals. The present findings reflect similar results found by Lasgaard et al. (2009). Lasgaard et al. (2009) conducted a study examining loneliness among adolescents diagnosed with ASD and found that those individuals who reported having social support from family members also reported less experience of loneliness, which in turn may have influenced feelings of depression.

As found by Rice, Harold, Shelton and Thapar (2006), depression symptoms among a sample of non-clinical children and adolescents was directly related to family conflict. Specifically, children and adolescents, particularly those with a family history of depression, who experienced familial conflict, also exhibited a markedly increased risk of developing depression (Rice et al., 2006). Further supporting the present study's findings, Kelly, Garnett, Attwood, and Peterson (2008) conducted a study examining the relationships between the anxiety and depression children with ASD experienced as

moderated by factors related to familial and peer relationships. Specifically, Kelly et al. (2008) examined how family cohesion versus family conflict and peer support versus bullying impacted the children with ASD's levels of anxiety and depression. The results of the study indicated that as family conflict increased, symptoms of anxiety and depression among the children with ASD also increased, promoting support for the notion that the family environment and relationships within that environment directly impact symptoms of depression for individuals with ASD (Kelly et al., 2008).

The second research question examined the presence of any significant relationships between participants' gender and depressive symptoms. The results did not indicate a significant relationship between gender and depression. Although Essau et al. (2012) reported that depression among the general population occurs more frequently in females as compared to males, the present findings are consistent with previous research conducted by Lai et al. (2011), who did not find significant gender differences within their sample of individuals with ASD. Lai et al. (2011) looked at a sample of adults with ASD who reported significant levels of anxiety or depression, and found that no gender differences existed. As noted by Ghaziuddin et al. (2002), females and males with ASD present characteristics of autism differently, which may in turn affect the occurrences and presentation of depression across genders within this population.

The third research question sought to determine the presence of any relationship between past involvement in extracurricular activities and depression symptoms. The statistical analysis revealed that the relationship between participation in extracurricular activities and depression was significant. Specifically, those participants who reported

engaging in extra curricular activities while growing up had statistically significantly lower depression means when compared to the individuals who did not participate in extracurricular activities. These findings are in alignment with previous research conducted by Mason, Schmidt, Abraham, Walked, and Tercy (2009) within the general population. Mason et al. (2009) studied a group of adolescents and found that those who engaged in more extracurricular activities reported lower depressive symptoms. Koegel, Ashbaugh, Koegel, Detar, and Register (2013) examined the effects of extracurricular social activities on high school students with ASD. They found that when the social activities centered on the high school students with ASD's areas of interest, the participants reported greater feelings of happiness. These findings suggest that individuals with ASD may benefit most from extracurricular activities related to their specific area of interest (Koegel et al., 2013).

The fourth research question examined whether or not participants' reported number of friends was related to experienced symptoms of depression, and was not significant. Previous research has suggested that friendships for individuals with ASD offer both positive and negative effects, and can be difficult to understand. Engaging with others may aid individuals with ASD in generalizing newly learned social skills; although, on the other hand, the challenges related to interpreting the social world may leave individuals with ASD at greater risk for being rejected and feeling lonely (Chamberlain, Kasari, & Rotheram-Fuller, 2006). Additionally, individuals with ASD are more likely to identify others as their friends, while those individuals they identified

are less likely to name the individuals with ASD as their friends (Chamberlain et al., 2006).

The fifth research question examined whether or not there was a relationship between participants receiving counseling services in the past and reported levels of depression; no significant differences were found. Notably, this particular item was added to the survey after it had already been completed by a majority of participants, therefore this analysis includes a relatively smaller number of participants ($N = 50$). Additionally, the results of this particular item should be interpreted with caution due to the disparity among the number of participants in each condition. There is limited previous research available that focuses on counseling as an intervention among individuals with ASD. The research that has been conducted in this area typically focuses on reducing anxiety, or remediating social deficits (White et al., 2010).

Qualitative Analysis

The qualitative information gained from the present analysis adds breadth to the existing body of knowledge regarding individuals with ASD and depression. The current study found that five themes emerged from the thematic analysis conducted, which was based upon the framework developed by Braun and Clarke (2006). The five themes that emerged included emotional experiences, interpersonal relationships, isolation, sensory experiences, and having a unique perspective. Each theme is comprised of both a positive and negative aspect, as participants identified aspects of each theme to be either an asset or a hindrance.

Emotional experiences. Participants involved in the present study identified being emotionally detached as beneficial in some scenarios, and as a detriment in others. Participants who indicated emotional detachment as a positive attribute of ASD noted situations in which they had been able to perceive things in a logical and rational manner rather than becoming overly emotional and irrational. Those participants who identified emotional detachment in a negative manner recalled moments when they felt they should have experienced more connection during times they were unable to relate to others, or times when they responded to a situation in an overly emotional manner. As noted by Laurent and Rubin (2004) the ability to emotionally regulate plays a significant role in the social competency of individuals with ASD. Emotional regulation is not simply the ability to inhibit specific emotional responses or remain calm when in a highly emotional state, but it is the combined abilities of experiencing, recognizing and expressing emotions within a variety of social contexts. Several factors impact an individual with ASD's ability to effectively emotionally regulate including the degree to which an individual is capable of perspective taking, allowing for the ability to accurately perceive social situations and make predictions about others' behavior. Additionally, those individuals with ASD who experience difficulty tolerating sensory information and experience high levels of arousal typically demonstrate challenges regulating their emotional responses to that information. Additionally, individuals with ASD who are able to reflect on their own emotional experiences are more likely to exhibit the ability to effectively emotionally regulate (Laurent & Rubin, 2004).

Interpersonal relationships. Participants identified interpersonal relationships as both a challenge to be overcome, as well as one of the positive aspects of growing up with ASD. Participants who identified interpersonal relationships as positive noted support from family members and connecting with others who have ASD as beneficial aspects of growing up with ASD. Awareness of supportive interpersonal relationships may serve as a protective factor against the development of depression for individuals with ASD. Vickerstaff, Heriot, and Lopes (2006) found that individuals with ASD who had lower self-perceived social competency reported higher levels of depression. Vickerstaff et al.'s (2006) results support the notion that awareness of social deficits may be associated with a greater risk of depression among individuals with ASD (Wing, 1992).

Muller, Schuler, and Yates (2008) conducted a qualitative analysis of interviews with young adults with ASD, and found that social experiences were a key feature for most participants. Muller et al. (2008) identified several themes in their study that negatively affected their participants' ability to engage in fulfilling social interactions, including communication difficulties, difficulty initiating, and overall lack of social awareness. Many participants of the present study identified the same issues for themselves, which they indicated negatively affected their own interpersonal relationships. Participants of the present study as well as those in the Muller et al. (2008) study indicated a desire for intimacy and to contribute to the world around them.

One of the commonly described negative aspects of interpersonal relationships is bullying. Many participants reflected on challenges they experienced due to being

bullied while growing up. Research has demonstrated that being a victim of bullying is associated with a number of negative outcomes, including depressive symptomatology (Cappadocia, Weiss, & Pepler, 2012). Previous research suggests that victimization rates for adolescents with ASD are relatively high. Sterzing, Shattuck, Narendorf, Wagner, and Cooper (2012) sought to provide a national representation of bullying involvement for adolescents with ASD and determined that 46.3% of adolescents with ASD experience bullying as victims. Research has shown that adolescents with ASD were more likely to be victimized if they were of non-Hispanic ethnicity, demonstrated characteristics of ADHD, exhibited relatively lower social skills, had the ability for reciprocal conversation, and spent relatively more time in general education (Sterzing et al., 2012). Cappadocia et al. (2012) found that children with ASD who were bullied were much more likely to have a preexisting comorbid internalizing disorder, fewer friends, and to exhibit communication difficulties.

Isolation. Participants reflected on social isolation as both positive and negative. Those individuals who described isolation as positive provided illustrations of time spent focusing on creative endeavors, or focusing on their specific areas of interest. O’Neill (1998) described her own experiences as an individual with ASD in her article, *Autism: Isolation not Desolation – A Personal Account*. O’Neill (1998) noted, as many participants in the present study echoed, that she experienced a rich inner life and that her isolation need not be equated as negative. O’Neill stated, “It is not desolate and gloomy here inside myself. It is rich, rewarding, shifting, changing, facets of colour, and vivid sensory impressions that encompass all of my being” (p. 200, 1998). In a similar vein,

several participants in the Muller et al. (2008) study reported that alone time was very important for rejuvenation, and wanted others to understand their need for some solitude.

On the other hand, previous research also supports the theme of negative isolation, described by many participants as a disadvantage of having ASD. Muller et al. (2008) found that isolation was a key feature for most participants in their qualitative study. Muller et al. (2008) noted that, like many participants reported in the present study, feeling misunderstood and rejected intensified their experiences of feeling isolated. Similar to some participants in the present study, participants of the Muller et al. (2008) study explained that their lack of social awareness and social understanding enabled the isolation, which was perceived as negative.

Sensory experiences. Many participants of the present study identified sensory experiences as either a beneficial aspect of having ASD, or a challenge in a variety of situations. Previous research has also identified that many individuals with ASD experience sensory related challenges that are reflected as either positive or negative depending on the context (Barnhill, 2007). As noted by Barnhill (2007), individuals with ASD may experience sensations in an over- or under-responsive manner and either scenario may be equally distressing or pleasant. Barnhill (2007) asserts that the frequency and intensity coupled with how the individual with ASD interprets and expresses information may moderate how these events are interpreted. Work conducted by Smith and Sharp (2013) furthered the study of sensory experiences among adults who were identified as having Asperger's syndrome. Like the participants in the present study, Smith and Sharp's (2013) participants described sensory experiences as

simultaneously distressing and pleasurable. Generally, participants articulated that their heightened sensory experiences could be advantageous as they provided them with unique and specific skills. Those specific skills were noted to be a source of pride by many participants, and several individuals indicated that their heightened response to sensory stimuli helped them to develop self-awareness and resilience, which in turn allowed them to develop coping skills in times of distress. On the other hand, many participants also identified aspects of responses to sensory stimuli resulting in negative emotions such as fear or anger. Several participants reported that their heightened response to sensory stimuli resulted in their avoidance of social situations, which typically included a barrage of sensory information that at times became too much to process (Smith & Sharp, 2013).

Unique perspective. Individuals who participated in the present study identified their perspective as being either an asset of having ASD or a hindrance. Several participants identified their areas of specific interest as a benefit, a way to cope with the world, and other participants explained that their unique specific interests set them apart from other people and, therefore, further isolated them.

Griffith et al. (2012) found that individuals with ASD typically perceived neurotypical individuals to experience a much easier time traversing through life. Griffith et al.'s (2012) participants reported experiencing difficulty with employment and mainstream supports, which they perceived to be more challenging for them than they imagined it would be for neurotypical individuals. Additionally, Griffith et al. (2012) found that their participants believed they were perceived by others to be “odd,” which

may have compounded feelings of depression. The findings presented by Griffith et al. (2012) align with themes that emerged from the present study. For example, multiple participants indicated that they felt as though most other people generally misunderstood them.

Limitations

The instrumentation and research design utilized presented several significant limitations to the results. The study was based upon a survey created by the researcher, which limits its validity and reliability as it has never been utilized or studied previously. The survey required respondents to answer questions in a variety of formats pertaining to a wide range of experiences therefore further limiting the study by making the information gained difficult to summarize or quantify. Also, because the researcher created the survey, the topics addressed are based upon what the researcher and the research team determined to be relevant, and therefore may be missing important information. An additional limitation of the study includes the self-report format of the survey and its reliance on the accuracy and honesty of the participants. Reliance on the accuracy and truthfulness of the participants presents a limitation, as the information gained may be inaccurate, and there was no way to determine whether or not participants understood each item. Participants were assumed to be truthful when reporting a previous diagnosis of an ASD, as well as when recounting their experiences. Moreover, many of the survey items may be interpreted in a subjective manner by the respondent, which further limits the interpretation of gained information.

A further limitation includes the fact that the data utilized were culled from archival data. The use of archival data poses limitations to the present study, as it is limited to the information previously gathered. Because the data analyzed was previously gathered, important material may be missing and the content may be limited due to the manner in which it was collected. Also among the limitations is that participants were made of a convenience sample, although convenience sampling is a common practice within psychological and behavioral research. Convenience sampling created several limitations regarding the generalizability of the study results. Because convenience sampling is comprised of accessible subjects easily recruited, it results in a sample that is not representative of the entire population and does not provide representative results. The sample was comprised of individuals who had access to a computer with Internet capabilities, therefore excluding participants who did not have access to such resources. The participants were a fairly homogenous group of individuals, as a majority of the participants reported being white or Caucasian. Based upon the relatively homogenous make-up of the sample, generalizations regarding the results are limited.

Additionally, it has previously been thought that a mixed methods approach including both quantitative and qualitative research has been a limitation. Recently, research has demonstrated support for utilizing mixed methods approaches in psychological research. Tashakkori, Teddlie, and Sines (2012) noted that a mixed methods design allows for a broader approach, which not only focuses on numeric data

and prediction, but also highlights the participants' individual characteristics and the contextual implications in terms of responses.

Implications for Practice

Several findings of the present study provide implications for the practice of school psychology. Individuals who reported a positive relationship with their parent(s) had significantly lower depression means as compared to participants who indicated a negative relationship with their parent(s). In addition to serving as a potential protective factor for the development of associated mental health conditions, positive parent relations have also been demonstrated to provide beneficial outcomes in regards to education. For example, Gonzalez-DeHass, Willems, and Holbien (2005) determined that improved parent and student relationships were associated with students' increased motivation, engagement, perceived self-competence, self-regulation, and goal orientation. Field and Hoffman (1999) found that parents who experienced positive and supportive relationships with their children with ASD, who modeled skills necessary for self-determination, saw beneficial outcomes in their children. For instance, those parents who provided their children with the opportunities for self-exploration, choices, and allowed for some risk-taking while also providing guidance, saw significant benefit in their child's ability for overall self-determination (Field & Hoffman, 1999).

School psychologists can provide support in the development of positive parent and child relationships through psychoeducation and training. Several aspects of familial interaction have been identified as critical in the development of self-determination among individuals with ASD (Field & Hoffman, 1999). For instance, the school

psychologist should attempt to understand the individual family characteristics, while helping family members understand their interactions based on roles, expectations, and adaptability. Further, family function is an important aspect for consideration when attempting to facilitate positive relations, which includes daily care responsibilities, recreation, and availability of resources (Field & Hoffman, 1999).

Additionally, the results of the present study indicated that the relationship between participants who engaged in extracurricular activities exhibited significantly lower depression means as compared to those individuals who did not participate in extracurricular activities. These findings are noteworthy for the field of school psychology, and further inquiry may provide directions regarding which type of extracurricular activities are most beneficial for individuals with ASD. For example, Koegel et al. (2013) found that extracurricular activities, which included an individual's specific area of interest and were also structured, increased the individual's motivation for participation. Additionally, when an individual's area of interest was the focus of the extracurricular activities, there were substantial increases in the quantity and quality of social interaction. Koegel et al.'s (2013) findings are salient as participation in structured activities intended to increase social skills and social awareness among adults with ASD has been demonstrated to be associated with reductions in self-reported depression (Hillier, Fish, Siegel, & Beversdorf, 2011).

Future Directions

The current study provided two factors related to statistically significant differences among participants' reported depression mean composite scores, and it would

benefit the community to explore these factors in future research. Firstly, individuals who reported a positive parent relationship also reported significantly lower depression means than those individuals who identified their parent relationships as negative. Much of the previous research conducted regarding family interactions and individuals with ASD has focused on the impact of ASD symptomatology on parent and sibling stress and depression (Kelly et al., 2008). Future research could expand upon the findings of the current study by attempting to identify specific variables that facilitate positively perceived parent relationships among individuals with ASD. Secondly, the current study also identified that participants who reported that they participated in extracurricular activities while growing up, also reported statistically significantly lower depression mean composite scores as compared to those participants who did not engage in extracurricular activities.

Interestingly, of the 126 participants who provided information regarding their gender, five participants reported being transgendered or genderqueer. Research among individuals with ASD who also report a nonconforming gender identity is limited, but researchers have determined that nonconforming gender identity occurs more often in individuals with ASD as compared to the general population (Van Schalkwyk, Klingensmith, & Volkmar, 2015). As noted by Parkinson (2013), the occurrence of high functioning ASD is higher among individuals who identify as transgendered as compared to the general population. It would benefit the ASD community to further investigate gender identity among individuals with ASD, and the experiences of those individuals with ASD who have a nonconforming gender identity.

Many participants who described interpersonal relationships as a challenging aspect of ASD recalled experiences of bullying that had a negative impact on them while growing up. As noted by Sterzing et al. (2012), adolescents with ASD are very likely to be victims of bullying. It would be beneficial to further explore protective and risk factors when experiencing bullying, and also to explore the effects of a variety of bullying related school based interventions. Sterzing et al. (2012) noted the importance of school-based interventions in order to address the characteristic deficits of ASD as well as commonly occurring comorbid disorders. Additionally, because bullying was more likely to occur with increased exposure to the general education setting, future research should examine the effects of protective peer groups and targeting the empathy and social skills of the general education students (Sterzing et al., 2012).

Previous research indicates that adolescents with ASD who exhibit social impairments report feelings of loneliness and a desire to have meaningful social relationships (Koegel et al., 2013). Additionally, it has been previously suggested that the social impairments that individuals with ASD experience increase the risk of the development of co-morbid disorders, such as anxiety and depression (Koegel et al., 2013). Based on the results of previous research, as well as the findings of the present study, future researchers should consider the importance of exposing individuals with ASD to opportunities for social skills remediation and interaction with others through extracurricular activities. According to Muller et al. (2008), future research should investigate the impacts of structured social activities and facilitated social interactions on experiences of social rejection and isolation.

Finally, as the survey utilized in the present study presented several significant limitations, further research is warranted with an improved survey instrument. The present survey could be improved by presenting items in a consistent method, as opposed to in a variety of formats thus allowing for more systematic analysis of data. Future research should be conducted examining the same constructs with a validated tool intended to measure symptoms of depression. Further, the current study was comprised of a fairly homogenous sample, and future research utilizing a more representative sample is necessitated.

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APPENDIX A

Survey

Growing up with Autism from the Perspective of Adults with Autism Spectrum Disorders
Survey Items

1. Gender:
2. Race/Ethnicity:
3. Age:
4. Please indicate the highest level of education you completed:
 - a) Some high school, no diploma
 - b) High school diploma or equivalent (i.e. GED)
 - c) Some college, no degree
 - d) Trade school, technical, or vocational training
 - e) Associate's degree
 - f) Bachelor's degree
 - g) Master's degree
 - h) Doctorate degree
 - i) Other (please specify)
5. How old were you when you first learned you had autism?
6. What kind of autism spectrum disorder do you have?
 - a) Pervasive developmental disorder not otherwise specific (PDD-NOS)
 - b) Autism
 - c) Asperger Syndrome
 - d) Other (please specify)
7. Have you ever been diagnosed with a form of depression?
 - a) If so, please describe
8. Have you ever felt that you were given the wrong diagnosis?
 - a) If so, please describe
9. Have you ever received counseling or mental health services?
10. Have you previously, or are you currently taking medication for any of the following:
 - a) Anxiety
 - b) Depression
 - c) Attention Deficit/Hyperactivity Disorder (ADHD)

11. Have you ever wished that you did not have autism?
12. If you have ever wished you did not have autism, why did you feel this way?
13. Do you think other people look at you differently because you have autism?
 - a) If so, how do they look at you differently?
14. How often do you talk to others about having autism?
 - a) Never
 - b) Occasionally
 - c) Often
15. How many friends do you have?
 - a) 0
 - b) 1
 - c) 2-3
 - d) 4-5
 - e) More than 6
16. Growing up, did you participate in activities outside of school?
 - a) If so, what activities did you participate in?
17. What kind of services did you receive while in school?

If you have any siblings, please answer the following questions about a sibling you feel close to

18. How old is your sibling
19. How would you describe your relationship with your sibling?
20. Do you ever feel frustrated that you have autism and your sibling does not?
21. How old were you when you realized you were different from your sibling?
22. Are you jealous of your sibling?
23. Do you feel that your sibling is protective of you?
24. How does your sibling treat you?

25. Do you feel you are close to your sibling?
26. Do you have more or less friends than your sibling?
27. Do you think you need more help than you sibling?
28. If so, how much more help do you need than your sibling?
29. Do you feel that you get more attention than your sibling?
30. How would you describe your relationship with your parents?
31. Do you feel that the people you know understand you?
- a) All the time
 - b) Most of the time
 - c) Some of the time
 - d) Not at all
32. Do you feel the people you know listen to you?
- a) All the time
 - b) Most of the time
 - c) Some of the time
 - d) Not at all
33. Please tell us the best thing about growing up with autism. Give examples if you would like.
34. Please tell us the most difficult thing about growing up with autism. Give examples if you would like.
35. Please tell us something you enjoy doing.
36. Please tell us something funny that has happened to you because you have autism.

37. What advice do you have for others with autism or for those who have a sibling with autism?
38. What does autism mean to you?
39. How often do you find yourself sleeping more or less than usual?
- a) Never
 - b) 1 day or less each week
 - c) 2-3 days each week
 - d) Almost everyday
40. How often do you find yourself becoming easily fatigued?
- a) Never
 - b) 1 day or less each week
 - c) 2-3 days each week
 - d) Almost everyday
41. How often do you find yourself eating more or less than usual?
- a) Never
 - b) 1 day or less each week
 - c) 2-3 days each week
 - d) Almost everyday
42. How often have you found yourself focusing on activities you usually enjoy?
- a) Never
 - b) 1 day or less each week
 - c) 2-3 days each week
 - d) Almost everyday
43. How often do you find yourself having difficulty concentrating?
- a) Never
 - b) 1 day or less each week
 - c) 2-3 days each week
 - d) Almost everyday
44. How often do you find yourself having negative thoughts about yourself or your abilities?
- a) Never
 - b) 1 day or less each week
 - c) 2-3 days each week
 - d) Almost everyday

45. How often have you found yourself feeling irritable?

- a) Never
- b) 1 day or less each week
- c) 2-3 days each week
- d) Almost everyday

46. How often do you find yourself having difficulty making decisions?

- a) Never
- b) 1 day or less each week
- c) 2-3 days each week
- d) Almost everyday