EFFECTS OF ANXIETY DISORDERS ON LIFE OUTCOMES OF ADULTS WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Brianna Herold: Effects Of Anxiety Disorders On Life Outcomes Of Adults
With Autism Spectrum Disorder
(Under the direction of Mark Klinger)

With growing prevalence rates, the population of individuals with autism spectrum disorder (ASD) is shifting, as those who are children enter adulthood. Autism has high comorbidity with anxiety disorders. This study examines how the presence of ASD and anxiety affects varying life factors such as friendships, employment, and quality of life. The survey, completed by 97 caregivers of clients of the North Carolina TEACCH Autism Program, examined the presence of comorbid anxiety disorders and their relationship to adult outcomes. Results indicated the presence of anxiety symptoms impacted quality of life and daily living skills for individuals with ASD. Factors such as overlapping symptoms for dual diagnosis and the use of caregiver report were limitations within this study. With 27% of the sample having an anxiety disorder, findings highlight needed assessment to impact anxiety on adult outcomes for individuals with autism. Further research is essential to assist the growing ASD population.

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LIST OF ABBREVIATIONS

ADAMS Anxiety, Depression and Mood Scale

ADL Activities of Daily Living Scale

ASD Autism Spectrum Disorder

CARS Childhood Autism Rating Scale

CBT Cognitive Behavioral Therapy

CDC Centers for Disease Control and Prevention

HFA High Functioning Autism

ID Intellectual Disability

IQ Intelligence Quotient

PECS Picture Exchange Communication System

PDD Pervasive Developmental Disorder

PDD-NOS Pervasive Developmental Disorder Not Otherwise Specified

QoL Quality of Life

SRS Social Responsiveness Scale

VABS Vineland Adaptive Behavior Scale

CHAPTER 1: INTRODUCTION

With increasing diagnostic rates of Autism Spectrum Disorder (ASD), the push for better diagnostics, treatment, and quality of life for individuals diagnosed has never been more pressing. Recent rates from the Centers for Disease Control and Prevention (CDC) report 1 in 68 children are diagnosed with this neurodevelopmental disorder. While researchers tend to focus on the early treatment and diagnosis of the disorder, what happens to the individuals with this lifelong disorder? Not only have life outcomes become a concern in individuals with ASD, but also further research has shown high comorbidity of other developmental and psychiatric disorders amongst those with an ASD diagnosis. Of children diagnosed with ASD, 72% also received a diagnosis of a comorbid Axis I psychiatric disorder (Leyfer et al., 2006). From the numerous psychiatric disorders, anxiety disorders are more common in children diagnosed on the spectrum than in typically developing children (Gillott, Furniss, & Walter, 2001). A metaanalysis showed that 39.6% of children with ASD also had at least one comorbid anxiety disorder (van Steensel, Bögels, & Perrin, 2011). The comorbidity of ASD and anxiety disorders may affect quality of life. In a study by Renty and Roeyers (2006) participants diagnosed with ASD had lower rates of gainful employment, in addition to higher rates of living at home with their parents or with professional support, despite their intelligence or level of functioning. Knowledge of the high rates of anxiety disorder in individuals with ASD begs the question of how this common comorbidity affects life outcomes. This study assessed the life outcomes of individuals with ASD who were diagnosed by the North Carolina TEACCH Autism Program. Assessment of possible anxiety allowed for a new perspective into the comorbid effects of ASD and anxiety disorders on adult life outcomes. The research will aid in not only gaining

knowledge on this topic but address areas of life affected such as education, relationships and occupation in relation to the overall quality of life of adults diagnosed with ASD.

Autism Spectrum Disorder

About one in six children were diagnosed with a developmental disability, such as cerebral palsy, intellectual disabilities, and ASD, between 2006 and 2008 (Center for Disease Control and Prevention [CDC], 2015). Over recent years, growing rates of diagnoses of ASD has caused concern leading to an increased need for additional information. ASD, a neurodevelopmental disorder characterized by deficits in social communication and interaction, in addition to restrictive, repetitive patterns of behaviors, interests and activities, has quickly approached a reported frequency of greater than 1% of the population (American Psychiatric Association, 2013). While the etiology of the disorder remains unknown, speculation points towards diagnostic criteria expansion, growing awareness, differences in methodology, or a true increase in the frequency of the developmental disorder (APA, 2013).

Diagnostics. Current prevalence rates by the Centers for Disease Control and Prevention (CDC, 2015) report about 1 in 68 children are diagnosed with ASD. The diagnosis is five times more common in boys than girls with a rate of 1 in 54 compared to 1 in 252 (Balo, 2012). When compared to the 2002 data, the report from 2008 showed an increase in the diagnosis of ASD of 78% (Balo, 2012). While the prevalence of ASD is not racially, socioeconomically, or ethnically specific, the highest occurrence rate is in non-Hispanic white individuals (CDC, 2015). In addition, research by the Center for Disease Control and Prevention shows children are being diagnosed earlier, 18% by the age of 3, though most are still diagnosed after age 4. This could be due to enrollment in school more clearly identifying symptoms. It is also more common for Asperger disorder, or high functioning individuals with ASD in the new diagnostic criteria, to be diagnosed later in childhood or adolescence (CDC, 2015). Diagnostics have changed, removing

specific disorders such as Asperger disorder and creating more of a spectrum with the fifth edition of the Diagnostic and Statistical Manual (APA, 2013). The criteria to meet ASD include: deficits in social communication and interaction and restrictive, repetitive patterns of behaviors, interests and activities (APA, 2013).

Treatment. The treatment of ASD often starts at a young age. Some parents use biomedical treatments as a form of intervention for their children. These often include either gluten-free or casein-free diets and adjusting to food sensitivities (Autism Society, 2013a). Communication is a major factor assessed and treated often in a behavioral approach, due to its significance as an essential ability throughout the life span (Autism Society, 2013b). Due to the key need for conversation and nonverbal possibility in children with ASD, devices such as Picture Exchange Communication System (PECS) are available to "talk" through the use of images (Autism Society, 2013b). Cognitive Behavioral Therapy (CBT) is another treatment approach. CBT stresses the importance of parents being involved in their child's treatment and their role in the daily routines throughout their lives (Moree & Davis, 2010). There is a delicate balance in using an interest as well in CBT for therapeutic gain versus causing possible problematic obsessions (Moree & Davis, 2010). The physical health of the individuals with ASD remains critical due to the fact they scored poorly as individuals with chronic illnesses in physical health (Kuhlthau et al., 2010). In adult treatment, it is important to note the lack of desire for friendships and relationships. Person-centered plans can aid in the use of supported or group living situations by providing the skills and meeting the needs of the individual (Plimley, 2007). Despite the early treatments, the life outcomes of individuals with ASD remain a significant concern.

Life Outcomes. Individuals with ASD often have difficulty with interpersonal relationships, poor social inclusion, and personal development through difficulty in

communication, all of which can affect the individual's life outcomes and emotional well-being (Plimley, 2007). This can affect the formation of friendships and relationships outside of the family. Higher rates of living at home with their parents or in professional support groups are reported for adults with ASD (Renty & Roeyers, 2006). A study in 2012 by Howlin and Moss reported that 48% of adults with ASD still lived at home. In addition to a decrease in independent living, individuals diagnosed on the spectrum had lower rates of gainful employment (Renty & Roeyers, 2006). Only 46% of adults diagnosed with ASD were employed or in school full-time (Howlin & Moss, 2012). Most of the adult research is on young adults in their 20s and 30s, with little on older adults. (Howlin & Moss, 2012). One of the few studies on an older population found adults with ASD had lower levels of adaptive functioning and experienced more behavioral problems (Totsika, Felce, Kerr, & Hastings, 2010). Further research would benefit this growing population of adults living with ASD. Moving forward it is important to examine the presence of anxiety disorders in the typical population, in addition to the co-morbidity of ASD and anxiety.

Anxiety Disorders

Anxiety disorders as defined by the 5th edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* are disorders sharing both fear and anxiety and behavioral disturbances. Fear is an emotional response to a threat while anxiety is the anticipation of a threat (APA, 2013). Of American adults ages 18 and older, approximately 40 million have an anxiety disorder (National Institute of Mental Health, 2013a).

Anxiety disorders are the most common mental illness is the United States (Anxiety and Depression Association of America, 2013). They often co-occur with other mental disorders of physical illnesses and last at least 6 months, but can become worse if not treated (National Institute of Mental Health, 2013b). For example, nearly 50% of people who have an anxiety

disorder also received a depression diagnosis (Anxiety and Depression Association of America, 2013). Anxiety symptoms often reported include, but are not limited to: constant worry, sweaty hands, poor concentration, muscle tension, physical weakness, palpitations, upset stomach and an inability to relax (Grohol, 2013).

Diagnostics. Anxiety disorders include separation anxiety, selective mutism, specific phobia, social anxiety (or social phobia), panic disorder, panic attack specifier, agoraphobia, generalized anxiety disorder, substance/medication-induced anxiety, and anxiety due to another medication condition (APA, 2013). Despite being highly treatable, many people do not receive treatment for their anxiety disorder (Anxiety and Depression Association of America, 2013). In addition, most of the individuals who have one anxiety disorder also are diagnosed with another anxiety disorder (National Institute of Mental Health, 2013a). Anxiety disorders are also commonly diagnosed with co-occurring substance abuse (National Institute of Mental Health, 2013b). The variation between the disorders lies in the object or situation causing the marked fear or anxiety (APA, 2013). Anxiety can occur in both young as well as older adults. For older adults, the most common anxiety disorder is generalized anxiety disorder (Anxiety and Depression Association of America, 2013). In children with anxiety disorders and specifically social anxiety disorders, peer interactions and struggling with friendships are commonly suggested by research (Chang, Quan, & Wood, 2012).

Treatment. Many treatments for anxiety disorders are effective. When treating anxiety disorders, it is important to study the triggers or sources of anxiety, the consequences, as well as what happens after the anxiety is triggered and the solutions or means to cope or reduce the anxiety for each individual diagnosed (Trembath, Germano, Johanson, & Dissanayake, 2012). Common treatments include medication, such as an anti-depressant, anti-anxiety and betablockers, as well as psychotherapy (National Institute of Mental Health, 2013b). Psychotherapy

has been the only effective treatment shown for specific phobias (Grohol, 2013). The combined treatment of both an antidepressant and cognitive behavioral therapy proved to be the most successful treatment in children ages 7 to 17 (Walkup et al., 2008). With treatment, outcomes of individuals with anxiety disorders are optimistic.

Life Outcomes. Individuals diagnosed with anxiety disorders have many opportunities for treatment options, which decrease or remove anxiety. A third of individuals who suffer from an anxiety disorder do not receive treatment (Anxiety and Depression Association of America, 2013). It appears the highest chance of being diagnosed and treated by a doctor is if the client has severe anxiety symptoms (Prins et al., 2011). Patients at follow-up possessing high levels of anxiety or depression were more likely to have a lower income or be unemployed because of the disorder (Prins et al., 2011). Some questions remain involving impact on quality of life for persons living with anxiety disorders due to it being one of the most commonly diagnosed psychiatric disorders. Studies conducted to date have shown a marked impairment in quality of life and other life outcomes (Mendlowicz & Stein, 2000).

Comorbidity of Autism Spectrum and Anxiety Disorders

Individuals with ASD often have comorbid psychiatric disorders. Seventy-five percent of individuals with ASD have at least one comorbid psychiatric disorder (Selles & Storch, 2013). Anxiety is the most common comorbid disorder in individuals with ASD. In one study, of children diagnosed with ASD, 40% also met criteria for an anxiety disorder (van Steensel, Bögels, & Perrin, 2011). Despite the reports of high comorbidity of anxiety disorders, differential diagnoses has been controversial due to the uncertainty of anxiety's relationship to the symptomology of ASD (Renno & Wood, 2013).

Diagnostics. Typical rates for anxiety disorder in elementary-age children are around 10% (Renno & Wood, 2013). Of individuals with ASD ages 10 to 14, almost 30% suffered from

social anxiety disorders (Howlin & Moss, 2012). When comparing autism-diagnosed individuals to those with pervasive developmental disorder not otherwise specified (PDD-NOS) or no diagnosis, results indicate those individuals with ASD saw a decrease in anxiety as communication deficits increased compared to those with PDD-NOS who saw an increase in anxiety as communication deficits increased (Davis et al., 2011). This is thought to be due to higher self-awareness of their social difficulties leading to more anxiety in higher functioning individuals. In children diagnosed with pervasive developmental disorder (PDD) 84% met the criteria for at least one anxiety disorder, 9% met criteria for panic disorder and 64% for simple phobia (Muris, Steerneman, Merckelbach, Holdrinet, & Meesters, 1998). The idea that anxiety is concomitant with ASD has increased interest, yet little has been done to evaluate the anxiety levels in the ASD population (Gillott & Standen, 2007). In a study by Renno and Wood (2013), individuals' clinical diagnoses were assessed and comorbidity was common for four anxiety disorders: separation anxiety disorder in 61%, social phobia in 91%, generalized anxiety disorder in 61% and obsessive compulsive disorder in 39%. Further research can assist in not only discovering the relationship between ASD and anxiety, but also aid in improving the treatment of the comorbidity and knowledge of specific anxiety disorder prevalence rates.

Treatment. The comorbidity of ASD and anxiety can result in worse life outcomes. Treatment of the anxiety can help to reduce the impairments caused by the comorbidity. Cognitive behavioral therapy for anxiety in children with ASD helped improve the positive treatment response after treatment in 78% of the group and the treatment gains were still present three-months post treatment (Wood et al., 2009). Despite the presence of effective treatments for anxiety disorders of individuals with an anxiety disorder, only 40% seek treatment within a year (Simon & Bögels, 2009).

Life Outcomes. Little research has directly examined how anxiety affects the life outcomes of individuals with ASD. One factor found to be highly correlated to life outcomes is loneliness in adults with ASD which resulted in increased rates of depression and anxiety and decreases in their self-esteem and life satisfaction, therefore affecting the well-being of the adults (Mazurek, 2013). It seems likely the comorbidity of anxiety and ASD can impair the lives of the individuals, thus reducing both their functioning and quality of life (Selles & Storch, 2013). With further research on the comorbidity and treatment of ASD and anxiety disorders, individuals diagnosed can benefit from more positive life outcomes.

Hypotheses

The purpose of this study is to build on previous research on the comorbidity of anxiety and ASD. This study expands the research about the life outcomes for individuals with these co-occurring diagnoses.

- 1. Individuals diagnosed with ASD who are higher functioning (in IQ, adaptive functioning, and with fewer ASD symptoms) will have higher levels of anxiety.
- 2. Individuals who have more severe anxiety symptoms will have worse adult life outcomes in terms of employment, friendships, and quality of life.

METHOD

Participants

This study recruited 97 caregivers of adults diagnosed at the North Carolina TEACCH Autism Program from 1965-2000. The individuals with ASD had current ages ranging between 21 and 64 years of age. The earliest families treated at TEACCH were recruited first, working towards those more recently served in order to recruit more individuals who are older than 30 years of age. Recruitment came from clinical records of clients seen at TEACCH for assessment and services. Parent's names and addresses were extracted from clinical records. Then, software

was used to assist in locating current addresses for those clients. Letters were mailed to the families for whom recent addresses were found to inform them about the study and request their participation in the study. An informed caregiver of the adult with ASD completed the survey. Sixty-eight mothers, twenty-three fathers, four mothers and fathers together, one sibling, and one aunt completed the surveys.

Measures

TEACCH Adult Outcome Survey. The TEACCH Adult Outcome Survey is a measure used to gain information on the life outcomes of the participant. The survey began with basic background and diagnosis information. The survey continued into other categories in the following order: language ability assessment information, educational background, current and previous past living situations, information on recreational and social life aspects, services used by the individual, job and work experience and independent living services. The survey concluded with information on benefits received by the government. The caregiver completed this measure. It was administered in the form of an electronic version or paper and pencil copy, based on the preference of the caregiver.

Anxiety, Depression and Mood Scale. The Anxiety, Depression and Mood Scale (ADAMS) is a rating scale used for populations with intellectual disability (ID). The scale includes 55 symptom items. These items are grouped into five factors: Manic/Hyperactive Behavior, Depressed Mood, Social Avoidance, General Anxiety and Compulsive Behavior (Esbensen, Rojahn, Aman, & Ruedrich, 2003). The scale has good internal consistency (Chronbach's alpha = .80 across the five factors, a test retest reliability of .81, and interrater reliability mean score of a .48; Esbensen, Rojahn, Aman, & Ruedrich, 2003).

Waisman Activity of Daily Living Scale. The Activities of Daily Living Scale (ADL) is

a caregiver survey of activities of daily living. The questionnaire contains 17 items and takes approximately 5 minutes to complete. The rating scale is rated on a 3-point scale, 0 = "does not do", 1 = "does with help", and lastly 2 = "does independently/on own" aiming to measure the level of independence when performing common daily activities (Maenner et al., 2013). The scale was an efficient measure over time, with weighted kappas between 0.92 and 0.93 (Maenner et al., 2013).

Social Responsiveness Scale. The Social Responsiveness Scale (SRS) is a caregiver completed screening questionnaire measuring the severity of social impairment in ASD across the entire range of the spectrum. The 15 to 20 minute questionnaire is comprised of 65 items measuring problems related to communication and behaviors reflective of ASD (Constantino & Gruber, 2005). Rated on a Likert scale format, response options comprise 1 = not true, 2 = sometimes true, 3 = often true and lastly 4 = almost always true. It is deemed user friendly and delivers a quick assessment of ASD symptoms (Constantino & Gruber, 2005). In the study by Bolte, Poustka, and Constantiono, internal consistency fell between 0.91 – 0.97, test retest reliability fell between 0.84 – 0.97, and interrater reliability fell between 0.76 and 0.95 in a cross-cultural validity study (Bolte, Poustka & Constantino, 2008). In addition, validity of the score includes discriminate validity, structural validity, concurrent validity, and factor structure surrounding autistic traits (Constantino & Gruber, 2005).

Quality of Life Questionnaire. Created by Schalock and Keither (1993), this 40-item scale addresses overall quality of life and can be completed by the individual or a caregiver. It takes into account various aspects of quality of life including personal life satisfaction, individual independence and productivity at work, feelings of empowerment and independence in living, and feelings of community integration and belonging. The scores range from 1 (low) to 3 (high).

An overall score for quality of life is computed ranging between 40 and 120. Designed as an outcome measure, the internal consistency of the total score is estimated at .90, with inter-rater reliabilities between .73 - .83 and a test-retest coefficient of .87 (Schalock, Keith, Hoffman, & Karen, 1989).

Childhood Autism Rating Scale. The Childhood Autism Rating Scale (CARS) is a behavior rating scale used in the diagnostic process to differentiate ASD from other developmental delays. The scale is completed by a clinician who rates fifteen items from one to four ranging from normal to severe (Garfin & McCallon, 1988). The criteria include such factors as relationships to people, imitation, use of objects, visual and listening responses, fear and nervousness, and verbal and non-verbal communication. The scores for the CARS range from 15 to 60; a score of 30 is deemed the cutoff for a diagnosis of ASD (Garfin & McCallon, 1988). The scale appears to be a reliable instrument with a kappa value of .63 and diagnosing a larger number of cases as autistic than the DSM-III-R criteria (Van Bourgondien, Marcus & Schopler, 1992). This measure was extracted from clinical records of participants when they were first diagnosed with an ASD between 1965 and 2000.

Vineland Adaptive Behavior Scale. The Vineland Adaptive Behavior Scale (VABS) is a test used to measure a person's adaptive level of functioning. Organized with a structure comprised of: Communication, Daily Living, Skills, Motor Skills and Socialization, the Vineland scale is an assessment tool used to diagnosis and evaluate special needs (Perry, Flanagan, Geier & Freeman, 2009). The scale, capable of measuring what an individual does, not what they are capable of doing, is completed by a caregiver or parent familiar with the individual (Carter et al., 1998). Test reliability intraclass correlation coefficients ranged from .98 to .99 and .99 for the adaptive behavior composite (Cabrera, Grimes-Gaa & Thyer, 2010). This measure was extracted

from clinical records of participants when they were first diagnosed with an ASD between 1965 and 2000.

Procedure

Caregivers of individuals diagnosed with ASD at TEACCH as children and who are now adults were provided with a survey to be completed. The survey could be taken either online or in a paper/pencil format depending on the preference of the caregiver. The survey had a completion time of approximately 90 minutes; \$20 dollars was provided to the caregivers of individual with ASD as compensation for their time. Informed consent was completed at the beginning the study. Participants completed six sections of the survey: the TEACCH Adult Outcome Survey, the TEACCH Health Survey, the Quality of Life Questionnaire, Anxiety, Depression and Mood Scale (ADAMS), Social Responsiveness Scale – Adult Version, and the Waisman Activities of Daily Living Scale. For the study on the relationship between ASD and anxiety, five of these scales were used in the assessment: Social Responsiveness Scale, Waisman Activities of Daily Living Scale, and the caregiver responses to the adult with autism's Quality of Life Questionnaire, the Anxiety, Depression and Mood Scale (ADAMS), in addition to additional information about the participant gained from the TEACCH Adult Outcome Survey. Additionally, CARS, VABS, and childhood IQ scores were extracted from participant's clinical records. If more than one score was present, the earliest score for each measure was used.

RESULTS

Sample Demographics

Of the 97 participants with ASD, 81% were male and 19% were female. The mean age of the sample was 34 years with ages ranging from 21 to 64 years old. Additionally, the mean childhood ASD diagnosis age for the sample was 8 years 3 months. The ethnic backgrounds of the sample were predominately white, with 79 individuals being Caucasian, 14 African

American, 2 Asian, and 2 bi-racial individuals. Two individuals were identified as Hispanic/Latino.

Co-morbid diagnoses for additional developmental disorders were common within the population. Due to the nature of the diagnosis for autism, including Asperger's and pervasive developmental disorder at the time, ID was a common comorbid diagnosis within the population. Of the sample, 58% had a diagnosis of ID at the time referred to as mental retardation. When questioned about how well the individual was capable of carrying on a conversation, caregivers reported 14% of adults had no trouble carrying on a conversation, 26% had a little trouble carrying on a conversation, 35% had a lot of trouble carrying on a conversation and 25% were unable to carry on a conversation. This measure of conversation was used as a proxy for adult IQ and was highly correlated with childhood IQ (r(67) = .60, p < .001). Intellectual functioning is important to recognize throughout the study due to the fact individuals with ASD who are high functioning are reported in the literature as more likely to receive some psychiatric disorders such as anxiety diagnoses.

Descriptive Statistics on Life Outcomes

Looking at education levels for individuals in the study, 29% received a regular high school diploma, 16% attended a 2-year or community college, 3% attended a 4-year college and 2% attended a graduate program. Living independently can often be difficult for individuals with ASD. The sample lived across a variety of locations with 12% living alone independently, 7% living in supervised housing, 39% living with parents, 23% living in a community group home, and 19% living in an intermediate care facility or institution. Only one individual from the sample was married. Per caregiver report, 67% reported being very satisfied, 26% somewhat satisfied and 5% unsatisfied or very unsatisfied with their current living arrangement.

Employment is another key element affecting the lives of individuals with ASD as employment can often give a sense of meaning. It was reported 64% of individuals had paid employment since high school and 49% reported having had a paid job within the last 2 years. The rate of current employment was 44%. The responses also endorsed a continued need for supports, accommodations or provisions, which were reported useful in maintaining employment. Caregivers responded with a 40% agreement that the individual needed additional career counseling, job training, and job assistance. Of those individuals in paid employment, the wages were low: 26% earned below minimum wage, 44% earned minimum wage, and 30% earned above minimum wage. This information is less surprising when examining the number of hours worked weekly. Only 7% of individuals who were ever employed worked 40 hours a week or full-time. The remaining responses included: 19% of individuals working 30 to 39 hours a week, 10% working 20 to 29 hours a week, 34% working 10 to 19 hours a week, 19% working 5 to 9 hours a week and 12% working less than 5 hours a week.

Descriptive Statistics on Anxiety

Descriptive analyses were conducted to examine occurrence and relationship of the two anxiety measures within this research sample. The two measures were a previous clinical diagnosis of anxiety and the ADAMS score on the general anxiety factor. A diagnosis of an anxiety disorder (including: obsessive compulsive disorder, specific phobias, social anxiety, panic attack and generalized anxiety) was reported in 27% of the sample. In addition, the Anxiety, Depression and Mood Scale (ADAMS) was used to measure the presence of current symptoms of anxiety rather than a measure of clinical diagnosis. Due to the overlap between symptoms of ASD and some anxiety symptoms, it often can be difficult to differentiate which symptoms are attributed to each diagnosis classification. The ADAMS scale for general anxiety was selected in order to assist in better capturing this aspect accurately in a population with

higher rates of ID. The ADAMS has a minimum score of a 0 and a maximum score of an 18. The mean on the ADAMS was a 4.95 with a standard deviation of 4.09. When comparing these two measures, a strong significant relationship was found. Individuals without an anxiety diagnosis had significantly lower scores on the ADAMS (M = 3.83, SD = 3.45) than individuals with anxiety diagnoses (M = 8.04, SD = 4.18; t(92) = -4.94, p < .001). This indicates the presence of an anxiety disorder diagnosis (history or current) and ADAMS general anxiety score (assessment of current symptom levels) were measuring related constructs.

Relation of Anxiety to Gender, Intellectual Functioning, ASD Symptoms Severity and Daily Living Skills

First, the relation of gender to anxiety was examined. Looking at the gender differences in rates of anxiety disorders within the sample, 24% of males in the sample had a diagnosis, whereas 39% of females had a diagnosis. However, this difference was not significant ($X^2 = 1.65$, p. = .20). Next, the symptom severity on the ADAMS was examined for the males (M = 4.88, SD = 3.98) and females (M = 5.22, SD = 4.63) on the general anxiety score (t(92) = -.32, t(92) = -.32). Gender differences were not significant for anxiety scores on the ADAMS. While higher rates of anxiety were expected in females as is true of the general population, this was not found in the present study. With a larger sample the expected relationship may have been found.

The next set of relational analyses were conducted to look at how various aspects of ASD were related to whether individuals had an anxiety disorder diagnosis, in addition to the severity of their current anxiety symptoms. The results from these analyses can be seen in Table 1 for anxiety disorder diagnoses and Table 2 for ADAMS General Anxiety scores. First, the relationship between intellectual functioning and anxiety was tested. The IQ of adults within the study was measured when the individual first sought treatment at TEACCH as a child. Individuals with an anxiety diagnosis had higher scores for childhood IQ (M = 74.33, SD = 23.38) compared to those without an anxiety diagnosis (M = 60.28, SD = 26.94; t(92) = -1.92, p = 20.94; t(92) = -1.92, t(92) = -1.92

= .06) (see Table 1), though this result was only marginally significant. Due to the lack of having an adult assessment for IQ, the variable closest to a measure of current intellectual functioning was conversation ability. The relation between anxiety diagnosis and conversation was examined. Conversation ability was not related to presence of an anxiety diagnosis (t(95) = .28, p = .78; see Table 1). Correlations for current anxiety symptom severity through report on the ADAMS were computed for both childhood IQ and conversation ability. No relation between the ADAMS General Anxiety score and IQ as a child (r(63) = .11, p = .40) nor conversation ability (r(93) = -.01, p = .95) was found. Therefore, having anxiety symptoms was not related to an individual's childhood IQ or adult conversation ability. This is surprising; as previous research showed individuals with ASD saw a decrease in anxiety as communication deficits increased (Davis et al., 2011) indicating higher intellectually functioning individuals were more likely to receive an anxiety diagnosis.

Next, the relation of anxiety disorder diagnoses and symptoms on the ADAMS were compared to ASD symptom severity as a child and as an adult. The Child Autism Rating Scale (CARS) was completed during initial diagnosis during childhood. A diagnosis of anxiety was not related to CARS scores for those with the disorder (M = 32.23, SD = 6.37) or those without an anxiety diagnosis (M = 34.88, SD = 6.95; t(70) = 1.48, p = .14). Analyses between the score on the ADAMS general anxiety measure and CARS score resulted in a medium sized negative correlation to the score on the CARS (r(68) = -.25, p = .04) showing that those with lower ASD symptom scores as a child on the CARS had higher anxiety symptoms as an adult. This result fits with previous research indicating those who are less impaired by ASD symptoms may be more likely to experience anxiety. The relation of the Social Responsiveness Scale (SRS) to anxiety was examined next. There was no relationship between an anxiety disorder diagnosis and scores

on the SRS (Table 1). Looking at the relation of SRS scores to ADAMS general anxiety scores, there was also a weak relationship that trended toward significance (r(91) = .19, p = .07).

Finally, the relationship between daily living skills and anxiety was examined. The Vineland Adaptive Behavior Scale was administered in childhood (M = 52.81, SD = 18.72). Childhood Vineland score was not related to a diagnosis of an anxiety disorder (see Table 1). Additionally, the Vineland was not related to the ADAMS general anxiety score (r(60) = .03, p = .83). Next, the relationship between anxiety and adult daily living skills was examined. The Waisman Activity of Daily Living Scale measured the adults with autism's current living skill level. Lower scores on the Waisman indicated poorer daily living skills. The presence of an anxiety diagnosis was unrelated to Waisman Daily Living Skills (see Table 1). However, the Waisman was significantly related to ADAMS general anxiety scores with a moderate sized negative relationship (r(92) = -.25, p = .02). This means having a previous anxiety diagnosis was not related to current daily living skills, however experiencing more current anxiety symptoms was related to poorer daily living skills.

Relation of Anxiety to Life Outcomes

Next, the relationship between anxiety and life outcomes was examined. First, employment was evaluated for its relationship to anxiety disorders. The results relating employment to anxiety diagnoses can be seen in Table 3. Table 4 contains results relating employment to ADAMS general anxiety scores. Of the individuals with an anxiety diagnosis, 42% were currently employed, very similar to the employment rate of those without an anxiety diagnosis (44%). A chi-squared test showed no difference in rate of employment between these with and without an anxiety diagnosis. Additionally, the relationship between current employment and ADAMS scores was not significant (t(91) = -1.76, p = .08) as anxiety symptoms for those who were currently employed (M = 4.17, SD = 4.05) did not differ from

those currently unemployed (M = 5.65, SD = 4.02). When comparing the amount of hours worked per week on a scale of 1 to 7 for those with an anxiety disorder (M = 2.18, SD = .81) and those without (M = 1.95, SD = .78), there was no relationship (t(59) = -.99, p = .33). However, the number of hours worked was related to ADAMS scores with a moderate negative relationship seen (r(58) = -.27, p = .04), showing that greater anxiety symptoms was associated with fewer hours worked weekly. The Vocational Index score was not related to diagnosis of anxiety t(94) = -.43, p = .67) nor ADAMS general anxiety scores (r(92) = -.15, p = .16).

Next, interaction with friends was examined to understand the social impact of anxiety. When assessing how often friends called or texted them in the last 12 months, those with anxiety (M = 2.88, SD = 2.23) and those without anxiety (M = 2.35, SD = 2.15) showed no difference in contact with friends (see Table 3). This question was reported on a scale of 1 to 7 with the score of a 2 being less than once a month and a score of a 3 being once a month for the amount friends communicated with the individual. The ADAMS General Anxiety score was also not related to this frequency of communication with friends (r(93) = -.01, p = .92). The frequency by which an individual with anxiety used electronic means to communicate with friends (M = 3.27, SD = 2.46) as compared to those without anxiety (M = 2.52, SD = 2.47) showed no relationship (t(95) = -1.32, p = .19). This was also on a scale of 1 to 7 with a score of a 2 being less than once a month and a score of a 3 being once a month. Again, looking at this factor, ADAMS anxiety was not related to electronic communication (t(93) = -.003, p = .98). The results indicate that although it may be expected that anxiety might affect communication with friends, anxiety had no effect on contact with friends.

Finally, the measure for quality of life was examined as an aspect for life outcomes. Having an anxiety diagnosis was statistically unrelated to Quality of Life total (t(91) = -.20, p = .84; see Table 3). However, there was a moderate negative correlation between the ADAMS

general anxiety score and the total for Quality of Life (r(90) = -.33, p = .001). Therefore, the higher the ADAMS anxiety scores, the lower the quality of life.

DISCUSSION

The purpose of this study was to better understand anxiety diagnosis and symptom severity within the adult ASD population. In order to ensure this, the relationship between anxiety and characteristics of ASD and to life outcomes were examined. In the sample of 97 caregivers of adults with ASD, a diagnosed anxiety disorder was reported in 27% of the sample. It is believed approximately 40% of those affected by ASD also meet criteria for an anxiety disorder (van Steensel, Bögels, & Perrin, 2011). This indicates the anxiety rate in the ASD population was somewhat lower within this study than compared to previous research. A possible reason for the difference may lie in the higher presence of ID within this population. Previous research indicates 31% of children with ASD were identified as having IQ scores in the range of ID 70 or less, and an additional 23% identified within the borderline range were 71-85 (Balo, 2014). Another rational for the lower rates of anxiety compared to previous research may be due to surveys being completed per caregiver report. This concept will be further discussed within the possible limitations section of this study. Similar to the general anxiety statistics, more of the women within this study had an anxiety diagnosis reflecting the gender differences typically seen in the general population, although this difference was not significant. This lack of relation of gender to anxiety in ASD was likely due to the small sample size of women with only 18 women in this study.

Surprisingly, results from this study showed only a few aspects of ASD were related to either having an anxiety diagnosis or anxiety symptoms on the ADAMS scale. Neither the presence of a diagnosis nor the score on ADAMS were correlated with childhood IQ or conversation ability. This is surprising given that previous research has shown a relationship in

intellectual functioning with co-morbid diagnoses of ASD and anxiety. For example, one study reported individuals with ASD had decreased anxiety as communication deficits increased (Davis et al., 2011). Therefore, individuals with more intellectual impairments were less likely to experience anxiety symptoms or co-occurring diagnoses of anxiety disorders. A factor to consider for the present study may be the lack of an accurate adulthood IQ score due to surveys being completed by a caregiver. While reporting an anxiety diagnosis is a clear indicator of presence, capturing anxiety levels experienced within the sample may be more difficult when not completed through a self-report. However, an important factor to consider once again is the ADAMS is a measure designed to be administered to populations with an intellectual disability. This may help explain why more anxiety symptoms may have been seen in this sample, especially for those with more intellectual impairments and may have eliminated the previously seen relationship between these co-morbid diagnoses by detecting more symptoms in those with ID.

The CARS, a measurement for ASD symptoms as a child, was not related to having an anxiety diagnosis. When comparing anxiety symptoms to the CARS, there was a moderate negative relationship demonstrating the higher the anxiety symptoms, the lower the CARS score or the less the ASD symptom severity. This fits well with previous literature. It was surprising the presence of an anxiety disorder did not relate to ASD symptom severity, yet current anxiety symptoms did correlate. The SRS score had no relationship with anxiety diagnosis or ADAMS general anxiety score. Again, this does not fit with previous research given those individuals with an anxiety diagnosis or symptoms did not relate to current deficits in communication as measured by the SRS for ASD. The differences in results for both the CARS and SRS may be due to the changing nature of both anxiety and ASD symptoms throughout the lifespan, though it

is surprising that the childhood measure was related but the adult measure was not. Both the presence of anxiety and ASD symptoms may increase and decrease throughout the lifespan.

The Vineland was not significantly related to having an anxiety diagnosis or ADAMS Anxiety scores. The Waisman showed no relationship with an anxiety diagnosis but was significantly related with ADAMS scores with a moderate negative relationship. These results indicated childhood scores for adaptive behaviors were not related to anxiety in adulthood, but adult adaptive behavior was related. This supports previous literature indicating anxiety in individuals who also have an ASD diagnosis can impair their lives and may reduce daily functioning (Selles & Storch, 2013).

Neither a diagnosis of anxiety nor current anxiety symptoms was related to current employment. Also, there was no relationship between having an anxiety disorder diagnosis and the hours worked weekly. The only employment measure found to have a significant relation was between the ADAMS and the amount of hours the individual worked weekly which showed a moderate sized negative relation. Those with higher anxiety worked fewer hours. This was surprising; it was expected that anxiety would substantially hinder employment within the ASD population. Some reasoning for the lack of relation between anxiety and employment may lie in the idea that employed individuals are more likely to be consistently faced with anxiety due to the many social interactions they must engage in, such as job stress and employment requirements. However, at the same time, they are receiving a great deal of practice coping with their anxiety in order to maintain their employment. These two factors may counteract each other, negating the effect of anxiety on employment. With reports being from a caregiver, how well the adult's anxiety levels were captured also remains an important question. Previous research suggested children had a better insight into anxiety than their parents despite an ASD diagnosis (Simon & Bögels, 2009). However, it is difficult to conceptualize the amount of

impact an intellectual disability disorder holds on the adult's perception or self-awareness of their anxiety, despite the prior literature. Therefore, it may be difficult for caregivers to report accurate measures affecting the questions on anxiety. If this was the case, this may minimize the relations seen. The other factor of employment assessed was the Vocational Index. Both an anxiety diagnosis and score on the ADAMS were not related with Vocational Index scores. Possessing an occupation can aide in giving purpose to life. Therefore, these are aspects requiring continued research in order for best life outcomes and integration into community.

The final aspects within the analyses were social interactions and quality of life. Social interactions, whether it was the number of times friends contacted them or the use of electronic communication with friends, showed no relation to anxiety. This result was not surprising given individuals with anxiety in previous research were on the higher end of the spectrum. The caregiver report may have affected these responses since they may have been unaware of social interactions or the individual's personal feelings of social anxiety. A moderate negative relationship between QoL and ADAMS scores was seen. As anxiety increased quality of life decreased. This result is consistent with previous research showing those with co-occurring ASD and anxiety diagnoses had poorer quality of life (Selles & Storch, 2013). These results indicate it is important to not only consider the diagnosis of an anxiety disorder, but also the severity of the symptoms and their ability to be altered over time. Therefore, whether diagnosed with anxiety or not, current symptom severity for anxiety may impact the lives of those with ASD.

Through review of the results in comparison to previous research findings, we can begin to better understand the effect of a co-morbid diagnosis anxiety on life outcomes for adults with ASD. Aspects of employment and friendships were not influenced by the presence of anxiety or an anxiety disorder, while quality of life and daily living skills were impacted. These results are consistent with previous findings showing those with co-morbid diagnoses had both reduced

functioning and quality of life (Selles & Storch, 2013). Other research shows loneliness was found to be highly correlated with increased rates of depression and anxiety, decreasing the individual's self-esteem and life satisfaction, therefore affecting their overall well-being (Mazurek, 2013).

Therefore, the results from this life outcome study are important as it adds to the previous literature showing both how childhood and adulthood factors affect anxiety and the effect anxiety has on elements of life outcomes. As reviewed in the analyses, individuals who have higher levels of anxiety currently as reported on the ADAMS had a lower in quality of life. Additionally, higher anxiety was related to a decrease in daily living skills. Anxiety importantly affects some aspects of life (quality of life and daily living skills) while not affecting others (employment and friendships). However, due to the cross-sectional nature of this study, it is unknown if individuals with higher anxiety levels had a lower quality of life and daily living skills, or if having a lack in these areas led to the higher anxiety levels. Future research needs to investigate why specific aspects of life are more impacted by anxiety than others.

Limitations

While this study begins to address many aspects of both dual diagnosis and life outcomes for adults with ASD previously not explored, the research has limitations. Due to the overlap in ASD and ID populations during the time period, the sample within this study appears different than what would be seen among younger individuals diagnosed today on the spectrum. This may cause differences in the reported rate of diagnosis of anxiety or reported symptoms because of possible decreases in intellectual functioning and insight. Additionally, the symptom overlap can cause concerns in distinguishing between ASD criteria being met versus a co-occurring anxiety disorder. The ability to more directly assess the adult with ASD would allow for a current

assessment of both ASD and anxiety symptoms and if the individual meets criteria for both diagnoses or if the perceived anxiety is more attributed to ASD symptoms.

Another major limitation is in the caregiver report. The sample for this study was overall of a lower intellectual functioning with 58% having a previous ID diagnosis. Because of this, the study relied upon a caregiver report, rather than self-report, as those with greater intellectual impairments may be less capable of providing self-reports. However, this may have made it difficult to fully capture personal views on concerns for quality of life, anxiety, and emotion-based responses. Measures applicable for the population, which could be completed by an informed caregiver, were of importance within the study. For example, other scores were used in order to capture intellectual functioning (i.e., conversation ability). For future research, it would be important and valuable to retest the same measures used during childhood in order to compare changes in the individuals now as adults. Addressing this concern could also assist with the cross-sectional nature of the research as a limitation. Therefore, testing individuals in childhood and adulthood could help determine causality and identify if a lack of specific skills leads to anxiety increases or if the higher anxiety levels impacts and impairs elements in the life of the individual.

Future Directions

This study begins to bridge the path for research to better understand the effect of comorbid anxiety and ASD on life outcomes. In future research, it is important to assess effective treatments for individuals with the co-morbid diagnosis in adulthood. In addition, further research on life outcomes for a sample of high-functioning individuals with ASD would be an interesting comparison to results from this study. In a study by Chalfant, Rapee and Carroll (2006) an investigation of effectiveness using CBT for high functioning autism spectrum disorder (HFA) children with comorbid anxiety disorder indicated the CBT treatment produced

significant change with 71% of those treated no longer fulfilling diagnostic criteria for anxiety. Individuals with HFA experienced anxiety in school, social and family experiences reported to have prevalence between 47 and 84% (Gillot, Furniss & Walter, 2001), so it seems important to focus on reducing anxiety in this group. The previous research on HFA is also important to note in comparison to this study. Despite knowledge about individuals who are HFA having high rates of co-morbid anxiety, the results from this study found individuals with ASD who were low functioning had similar rates of anxiety and anxiety symptoms. Finding little difference between the functioning level of individuals with ASD who had anxiety and those who did not, shows this co-morbidity may be important for future research. Is part of the reason anxiety has been associated with higher functioning individuals in previous research due to how anxiety was measured in those studies? It is possible that they missed anxiety symptoms in lower functioning individuals that this present study was better at detecting. Further research should directly examine this issue. It is important and necessary for both the creation and use of programming and treatment to target the population of individuals with ASD and anxiety across all levels of functioning. Future directions from this study could also address the need for both a caregiver report as well as self-report from the adult with ASD, in order to capture multiple perspectives. Additionally, further research could assess treatment needs and the effects of receiving services as a child in order to alter the life outcomes for the adult with ASD.

Implications for Rehabilitation Counselors

One of the most important aspects to alter for an individual with ASD and anxiety is the life outcome, specifically quality of life, which can be addressed through proper treatment and support throughout their lifespan. There is a pressing need to prepare for future demands as the diagnosis of ASD is increasing at a shocking rate. With the number of individuals on the spectrum multiplying, it is necessary to provide support to these individuals as they enter

adulthood. It can not merely be assumed all consumers hiring the general population are accustomed to working with individuals with ASD; special training or support will be needed to create effective employment outcomes. Additionally, it cannot be assumed the co-morbid diagnoses do not have an impact throughout the lifespan on various aspects. With results from this study in mind, rehabilitation counselors have the ability to meet the needs of individuals with ASD and anxiety diagnoses.

From a person-centered perspective, rehabilitation counselors can aid in employment, building skills for communication, daily living skills, and independence. By identifying potential risk factors with further research, the goal to guide improvements while influencing changes for those individuals with ASD merits recognition. As the global prevalence has increased, this thesis addresses the critical need for effective intervention and implementation for comorbid symptoms of anxiety impacting life outcomes for adults with autism.

Table 1
Anxiety Disorder Diagnosis in Relation to ASD Characteristics

	Anxiety diagnosis	No anxiety diagnosis	t	p
Childhood IQ	74.33	60.28	-1.92	.06
Conversation ability	2.65	2.78	.28	.78
CARS score	32.23	34.88	1.48	.14
SRS score	63.54	62.11	26	.80
Vineland score	54.06	52.36	32	.75
Waisman score	22.04	21.65	24	.81

Table 2

ADAMS Scores in Relation to ASD Characteristics

	r	N	p
Childhood IQ	.11	64	.40
Conversation ability	01	94	.95
CARS	25	69	.04
SRS	.19	92	.07
Vineland	.03	61	.83
Waisman	25	93	.02

Table 3
Anxiety Disorder Diagnosis in Relation to Life Outcomes

	Anxiety diagnosis	No anxiety diagnosis	t	p
Number of hours employed weekly	2.18	1.95	99	.33
Longest length of employment	2.19	2.34	.31	.76
Vocational Index	4.12	3.83	43	.67
Friends – Frequency of communication in last 12 months	2.88	2.35	-1.07	.29
Friends – Frequency of electronic communication	3.27	2.52	-1.32	.19
Quality of life score	78.08	77.41	20	.84

Table 4

ADAMS Scores in Relation to Life Outcomes

	r	N	p
Number of hours employed weekly	27	59	.04
Longest length of employment since high school	13	94	.21
Vocational index	15	93	.16
Friends – Frequency of communication in last 12 months	01	94	.92
Friends – Frequency of electronic communication	003	94	.98
Quality of life score	33	91	.001

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