

**Anxiety and Depression Symptomology in Adult Siblings
of Individuals with Autism**

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Abstract

Research into the effects that a child with Autism Spectrum Disorder (ASD) has on the family unit, specifically parents, abounded over the last several decades. The present study sought to evaluate the prevalence, sibship, age and biological sex effects on reported anxiety and depressive symptoms within a sample of adult siblings of an individual with ASD. **Population.** All participants (N = 500) were from the United States and were mostly Caucasian (93.2%) and even between biological male and female (51.2% female, 48% male), with an average age of 33 years old. **Method.** This exploratory study used an online survey, where respondents provided demographics and responded to a series of questions regarding their sibship. Respondents then took the Generalized Anxiety Disorder 7-Item Scale (GAD-7) and the Center for Epidemiological Studies Depression Scale (CES-D). Their total GAD-7 scores and CES-D scores were analyzed with their age, sibship (older/younger/same), age distance from their sibling with ASD and biological sex. **Results.** 64.2% of adult siblings of individuals with ASD reported clinically significant anxious scores and 85% reported clinical depression. Among adult siblings, older siblings were more likely to experience both depressive and anxious symptoms. Siblings 8-13 years younger and >25 years older than their siblings with ASD were at the highest risk of experiencing these symptoms to a more extreme degree than other age distance siblings. Lastly, there was higher rates of depression in female siblings, but no sex differences for anxiety. **Discussion.** Limitations to this study are explored. Further research is needed to examine whether these findings were mitigated by sample size, demographic representation, study question limits, geography

and more. The findings highlight the support needs of all members of the family of individuals with ASD.

Keywords: autism, siblings, anxiety, ANOVA, dissertation.

Chapter 1

Literature Review

Introduction to Autism Spectrum Disorder

According to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder in which the individual with Autism has social and communication deficits, as well as persistent behaviors or interests that may interfere in their daily life (5th ed.; DSM-5; American Psychological Association, 2013). Individuals with Autism may present with a variety of challenges. Difficulties in social interactions may include deficits in social-emotional reciprocity, such as the give and take in social interchanges, challenges in reading body language and gaining and maintaining relationships. Repetitive or restricted patterns of behavior may include repetitive motor behaviors or speech (such as hand-flapping or vocalizations), challenges with being flexible and requiring strict schedules or sameness in routine or activities, and sensitivity to and/or highly seeking various stimulus input. Many children with Autism seek sensory input such as vibrations and weighted blankets but may be sensitive to different light or sound inputs, with varying levels of reactivity to such stimulus (Fieldman et al., 2020).

While Autism as a diagnosis has been in the DSM since the 1980s, scientific and cultural understanding of Autism has grown tremendously during the last forty years since its conception as a neurodevelopmental expression. For example, the debate between the terminology and reference to a person either being Autistic or being a Person with Autism has switched back and forth and is currently still under change. For example, while the DSM and the APA tend to refer to individuals with ASD as a Person with

Autism, which is considered person-first language (that is, defining them as a person before defining them through their diagnosis), some argue that the being referred to as “Autistic” is more affirming, as the diagnosis carries strengths with it as well as challenges, and that the diagnosis is a part of the person’s identity (Brown, 2011). As the APA currently utilized the person-first language, that vernacular will be used for the purpose of this article and study.

The DSM-5 separates the “levels” of Autism into tiers of needed support (DSM-5, 2013, p., 52), such as bathing, eating, meal preparation, social interactions, communication and more, outside of what may be needed for a neurotypical child. These include Level 1; some support, Level 2; substantial support, and Level 3; very substantial support (5th ed.; DSM-5; American Psychological Association, 2013). The DSM-5 estimates that the prevalence of Autism to be approximately 1% of the United States and worldwide, which was confirmed in a more recent study which showed an upward trend in Autism diagnosing between 1995 (0.5%) to 2013 (0.9%) (Nevison & Zahorodny, 2019). Similarly, the Center for Disease Control and Prevention (CDC) reported that 1 in 44 children, or 1.8% of children, were diagnosed with ASD in 2016 (Maenner et al., 2020). According to Nevison & Zahorodny (2019), there does not seem to be any significant difference between race or ethnicity in terms of diagnostic risk of Autism. However, males are diagnosed 4.3 times more than females (Maenner et al., 2020). Autism can present with a variety of challenging behaviors, especially for children with the diagnoses, including sleep problems, aggression, social and interpersonal problems, and self-harm (Quebles, et al., 2020). There is also no difference in race or ethnicity in the presentation of challenging behaviors (Quebles et al., 2020). These challenges can be

mediated with a variety of approaches, such as behavioral learning, medications and early intervention (Quebles et al., 2020). However, as Autism is a spectrum, children present with a variety of behaviors which may or may not require intervention, familial adaptations, or environmental changes, and children respond to different techniques differently, and all of these interventions tend to include parental involvement between early diagnosis (around age 3) and young adulthood (age 18 and up) (Crone & Mehta, 2016). The behaviors, social interactions, interests, and stimulation sensitivities common to those diagnosed with Autism are often called “Broad Autism Phenotype,” or BAP (Howling et al., 2015, p. 707). These are characteristics shared by most individuals with Autism. BAPs are most often used to refer to characteristics commonly attributed to ASD which is present in someone who have not been diagnosed with Autism (Howling et al., 2015).

Children with Autism often have challenges with communication, behaviors and social interactions. These challenges can make learning and receiving support highly difficult. In school, many children diagnosed with ASD often need specialized education programs, often including a one-on-one support staff, a more structured academic day, adjusted disciplinary needs and more (Partlo, 2018). The changes in the typical approach to supporting a child with ASD are not limited to the classroom. Parents must change typical parenting approaches to support their child, in addition to seeking services and advocating for supports for their child with Autism (Cheung, Leung & Mak, 2019). These efforts in parenting styles and approaches often come at great cost to parents own mental health, stress, marriage and personal relationships. Additionally, neurotypical siblings tend to also feel the effects of household changes in parenting and support needs due to

their sibling with ASD, which may manifest in changes in prosocial behaviors and social adjustment (Rixon et al., 2021). These changes can be negative or positive, depending on the individual and the situation, as will be expanded upon later.

Research on Parents of Children with ASD

While the present study aims to evaluate sibling effects, the research pertaining to parents is relevant as parents and their interaction with all their children have a substantial impact on the outcomes of siblings. A significant portion of research regarding the familial experience of individuals with Autism Spectrum Disorder (ASD) has focused on the experience, supports and challenges faced by the parents of children with ASD (Hartley et al., 2010; Hsaio et al, 2016; Girli, 2018; Celia et al, 2020). For example, the concept of parents who become “Battle Weary” was explored by Celia et al (2020). This two-year study found that parents of children with ASD face constant issues of safety and equality within their communities, education system and even within their own families. Parents who have to constantly advocate and “battle” for their children suffer significant stress and become weary over time.

Girli (2018) explored the experiences of parents of children with ASD over their prime education years. They found that in addition to the consistent advocacy that parents have to make in order to ensure health and care for their child with ASD, as explored by Celia et al (2020), that they experience large shifts in mind-sets from their expectations from pre-birth to diagnosis. Additionally, parents experience a significant amount of guilt associated with leaving their children in other people’s care, demoralization from the consistent advocacy, lack of support and insecurity of system navigating. Girli (2018) additionally found that many parents of children with ASD lack sufficient social support

and become isolated. This isolation has large implications for familial and marital challenges, and individual mental health.

Parental Stress with ASD

While parenthood in general is a stressful role for any individual, the research clearly shows that parents of a child with ASD experiences an additional layer of stress due to their increased care provided and systematic navigation (Barroso et al., 2018). Children with ASD tend to require additional personal care, such as bathing, eating, meal preparation, as well as social support with making and keeping friends (Barroso et al., 2018). Similarly, parents often need to advocate within systems for their child's needs. For example, as communication is often a challenge for children with ASD, parents often need to communicate their needs, pains, likes and dislikes and more to teachers, doctors, and other paid social and behavioral supports (Boshoff et al., 2016). As children enter education environments, the roles of teachers also become much more significant in the lives of the children's parents. An example of this was shown by Hsaio et al. (2017) who explored the interplay between perceived stress and the parent-teacher relationship. Although good parent-teacher relationships appear to have a positive effect on the perceived health of the family unit, these relationships did not reduce the parent's overall perceived stress.

Parental stress was additionally studied by Bohadana, Marrissey & Paytner (2019) who found that over half of parents of a child with ASD exceeded the clinical cut off score for anxiety using an anxiety screener, and additionally more than 20% of remaining parents had elevated anxiety above common parental norms. Similarly, the parent's perceived quality of life also had a negative correlation with their stress (2019). That is,

the higher their stress, the lower their quality of life. This study showed that more than 70% of parents of a child with ASD have higher than typical parental stress and lower than typical quality of life.

As parental teams (e.g. mother and father teams, etc.) are known to be important to parent stress and satisfaction, it is also important to note the literature surrounding marital relationships for the parents of a child with ASD. Parental teams are able to support each other by both providing interpersonal care as well as relieving each other from care duties for breaks and respite, a factor which is much more challenging for single-parent caregivers (Papp et al., 2020). One study showed that when one partner is stressed or physiologically aroused (anxious, angry, etc.), that their partner is likely to mimic the physiological symptoms (Papp et al., 2020). Given consistent parental stress discussed earlier, parents are then likely to take on each other's emotions and have similar physiological responses to each other.

Research has shown that parents of children with ASD are much more likely than parents of neurotypical children to get divorced (Hartley et al., 2010). Divorce is more likely during the first eight years of the child's life, likely due to the increased stress from being caregivers and in navigating education and developmental healthcare/benefits systems (2010). Additionally, much of the clinical research surrounding Autism has been focused on genetics, potential chromosomal triggers and environmental triggers for ASD, and parents struggle with guilt for feeling potentially responsible for passing a gene or introducing some environmental trigger which contributed to their child's condition (Zhao et al., 2019). This guilt can be an additional cause of divorce and a desire to separate oneself from the child (Zhao et al., 2019). Similarly, parents of children with

ASD experience an extreme amount of anxiety in feeling pressured to foster the best outcomes for all their children, especially to help foster attachment with their children who face the challenges of Autism (O'Neill & Murray, 2016).

Culture and race can similarly have an impact on the experiences of parents of a child with ASD. Al Khateeb et al. (2019) conducted a systematic review of literature to find experiential differences between parents of children with ASD in Arab countries verses those of the United States. They found that in both Arab countries and the United States, many of the parental experiences were similar, such as extreme stress caused by the financial burdens of care, medical and treatment costs, increased rates of anxiety and depression (especially among mothers), reduced overall quality of life, frustrations surrounding available education, and social stigma surrounding the diagnoses and isolation (Al Khateeb et al., 2019). One area in which the Arab countries differed from the US was in religiosity. Arab countries tend to use faith more to cope, and while this is also seen to an extent in the US, religion is more often blamed for the condition of the child leading to further stress in parents in the US, such as the condition being a punishment for parental sin (Al Khateeb et al., 2019).

Parent General Coping

Given the general increase in stress that parents receive in caring for and raising their child with ASD, parents are faced with significant challenges in how to cope in nearly every aspect of life. However, even in regards to coping skills, parents are at a disadvantage due to reductions in parenting competence (Mohammadi et al., 2019). Parenting competence is important to understand how to help cope with challenges in education, care needs, schedules, navigating health and support systems and more. Given

the reduction in parental competency, parents of children with ASD are thus faced with greater reduction in coping abilities (Mohammadi et al., 2019).

Parents of children with ASD tend to become socially isolated as their time is devoted so heavily to the care and wellbeing of their child (Rudy, 2018). This isolation becomes even more deep with peers, as parents find that they become “experts” on Autism, while other parents know very little about it (2018). This chasm in knowledge creates a deeper divide between parents and others who would be their peers, as they have such differing parental experiences. This additionally puts a strain on parental marriages, especially when one parent engages in the childcare and advocates within support systems more for their child than the other parent does (2018). As a strong marriage is a protective factor for parental success and coping, this deepens the challenges and disadvantages faced by parents.

An individual’s ability to cope is associated mental health challenges such as depression and anxiety (Ang & Loh, 2019). Ang & Loh (2019) examined whether gender roles in parents of children with ASD affect their ability to cope. They found that while both parents were at a higher risk of depression than the general population. Specifically, mothers are more at risk of depression and challenges with coping than fathers, which Ang & Loh (2019) postulated may be due to their increased role in caregiving and advocacy. Additionally, they found that the primary coping strategy that both parents utilized is avoidance behaviors, such as self-criticism and internalizing (Ang & Loh, 2019).

Parent Supports and Interventions

As can be seen, special care and consideration for parents of individuals with ASD is especially needed. Given the special considerations and higher rates of depression, anxiety and more, Stoia and colleagues (2019) wrote some practice guidelines for clinicians supporting parents of children with ASD based upon the literature. Specifically, they recommend keeping close attention on symptoms of depression, anxiety, general stress and family/marriage stress, and to then normalize these experiences and provide treatment recommendations when symptoms are indicated (2019). They also recommend parent education on available resources, couple and family dynamics, and early intervention for all involved family members whenever possible.

Transportation and access to care for their child can be challenging for parents of children with Autism. These parents often feel stuck at home caring for their child and getting to an appointment alone may feel like a dereliction of their duties and cause additional stress (Rudy, 2018). Research is beginning to emerge on how to support parents of children with ASD in the comfort of their home, thus increasing the likelihood of participation in services and improving child and parent outcomes. A pilot study was conducted by Kihlthau and collages (2020), utilizing the Stress Management and Resiliency Training-Relaxation Response Resilience Program (SMART-3RP) for parents, which is an evidence-based and culturally sensitive mind-body intervention for stress. This program was adapted from its typical in-person group program model to be used virtually over 8 sessions, and utilized such activities as yoga, breathing awareness and body-scans. They found that even when this program conducted remotely (such as Zoom or FaceTime) that parents showed a measured increased in stress coping and a reduction in anxiety, depression, and overall worry (Kihlthau et al., 2020). This proved that while

isolation and leaving the house may be a challenge for many parents of children with ASD, that viable alternatives are becoming available and more common to support the mental health and wellbeing of parents.

ASD Effects on the Family Unit

As can be seen, parents of adults and children with Autism face a significant amount of stress, anxiety, financial burden and many other challenges related to their child's diagnosis. However, these stressors are not isolated solely to the parents, however. As parents experience the stresses of both perceived and real anxieties relating to their child's care, the family unit surely feels the effects of these anxieties. Often, family members are the primary caregivers for a child or adult with ASD, which can lead to fractured mental health, family cohesion and overall reduction of quality of life for the family members to take on these dual roles (Herrema et al., 2017).

Parents struggle with the task of fostering healthy attachment with their children no matter the development, diagnosis or challenges faced within the family unit. However, parents of children of Autism especially feel this challenge with their children, especially when there is a child who has special needs, such as Autism, as well as other neurotypical children (O'Neill & Murray, 2016). A study conducted by O'Neill & Murray in 2016 showed that parents who tend to have more of an anxious-attachment style are also more likely to have neurotypical children who struggle with anxiety. This shows a clear link between the parental perception and anxiety and the potential outcomes for their children, neurotypical and a-neurotypical.

As will be discussed in more detail later, neurotypical siblings of an individual with Autism tend to experience more expectations and pressures surrounding their role as

additional caregivers for their sibling with Autism, a phenomenon referred to as sibling parentification (Tomeny, Barry, et al., 2017). Both parents and sibling caregivers experience a high amount of measurable strain, as was found by a study done by Shivers, Krizova & Lee (2017). This stress was not limited to an age-range, but was across the lifespan of the caregivers of the individual with Autism. That is, the stress of caregiving and all the facets that come with it (system navigation, healthcare, provisions, legal aspects, etc.) are continued stressor, and not limited to the childhood of the individual with ASD. On the other hand, parents who are able to find coping mechanisms and are able to manage their anxiety, stress and mediate their parenting styles show much more positive resilience and general positive outcomes for both their child with ASD and their neurotypical children (McKee et al., 2020). Therefore, it is clear that parental stress and anxiety has a trickle-down effect within the entire family system, and whether a point of challenge or a strength, is felt by the entire family. Additionally, the functioning of the child with Autism, such as their motor function and severity of their diagnosis play a large mediating role in how affected the family members may be (Garrido, Carballo & Garcia-Retamero, 2020). The greater the functional challenges the child with ASD has, the greater the impact on the familial quality of life (Garcia-Retamero, 2020).

Of course, different people respond to stress in various ways, and may be affected by stress to differing degrees. Rivers & Stoneman (2008) found that temperament mediates the quality of relationship that neurotypical siblings have with their sibling with Autism. They also found that when there is differential parenting (treating some children different than others), sibling quality of relationship suffered (Rivers & Stoneman, 2008). That is, as children see or feel that their parents treat them differently than their siblings,

their relationship with that sibling is negatively affected. This has a large impact on the family dynamic as a whole and continues to add to the stress that the parents feel as their children do not have quality relationship with each other (Rivers & Stoneman, 2008).

Parents certainly notice these effects. However, when differential treatment was perceived by the neurotypical child, ratings of relationship quality were lower, although parents perceived this difference to be greater than that of the child's perspective (2015).

To add to the complexity of these situations, sibling responses and relationships are also highly mediated by the behaviors and aggression levels of the sibling with ASD (Braconnier et al., 2018). As Braconnier and colleagues found in their study, even if neurotypical siblings make significant efforts to have strong relationship with their sibling with ASD, the individual with Autism may not reciprocate these desires, and may shun relationship attempts or even be aggressive with their neurotypical siblings (2018).

Siblings of children with ASD are also more likely to react to the parents negatively, especially if they feel as though they are treated more poorly than their sibling with Autism (Rivers & Stoneman, 2008). These effects become much more prominent as the severity of autism symptoms increase (Dovgan & Mazurek, 2019). When the severity of the Autism symptoms are higher, the adjustment abilities and sense of familial coherence in the neurotypical siblings decreases (2019). Additionally, this effect is greatly increased when the individual with ASD also has comorbid diagnoses, such as anxiety, depression or other behavioral challenges, in addition to their autism (Dovgan & Mazurek, 2019). These additional challenges may also reduce the family's ability to gain greater cohesion, access services and supports, and may prevent mediation of caregiver anxiety and stress.

One way in which this lack of family cohesion can be seen is within family leisure time. Families with a person with Autism face numerous barriers to engaging in family leisure time as a group, and these challenges lead to decrease in family satisfaction, family communication and overall functioning (Walton, 2019). Family satisfaction is incredibly valuable to the outcomes that families experience. A study conducted by Laghi et al (2018) showed that overall familial satisfaction and functioning as the children were in early adolescence greatly predicted the quality of adult relationships that siblings have. These findings appear to be corroborated by Smith et al. (2015), who studied neurotypical adolescent siblings and their sense of family cohesion. They found that sibling adjustment and coping strategies predicted family cohesion, especially when the Autism severity was higher in their sibling. Thus, the challenges faced during adolescence, which is already a trying time for many parents and families regardless of the presence of autism, is mediated by the family relationship, which is in turn mediated by parental functioning.

The family unit is clearly a complicated and nuanced entity. Many factors affect the health and cohesion of a family unit, which may be further complicated by the presence of a family member with ASD.

ASD Effects on Neurotypical Sibling

Being the neurotypical sibling of a person with Autism comes with unique challenges. Throughout the literature, siblings without a diagnosis are commonly referred to as neurotypical (NT) and typically developing (TD). While these terms are used interchangeably in the research, the present study will refer to these siblings as *neurotypical*. The currently available research shows several key aspects of the

neurotypical sibling experience; general effects of social and psychological functioning, adolescent sibling experiences, adult sibling outcomes, and help seeking habits and available supports. A literature review done by Marquis, Hayes & McGrail (2019) identified 21 factors that contribute to the varying outcomes of neurotypical siblings of a person with ASD. These factors range from individual characteristics such as worry, age and other demographics, to the degree of function of the sibling with Autism, parental factors, socioeconomic status and even neighborhood characteristics. Specifically, they found that the age of the sibling and that of the family member with ASD was often identified in research, but does not seem to have a significant impact on anxiety levels in neurotypical siblings of someone with either Autism or Down Syndrome. NT siblings born after a child with ASD were found throughout the literature to be more at risk of anxiety, however, as did having additional care-giving roles for their sibling with Autism. Worry, or more specifically, concerns over the care of their sibling with Autism and their own future roles in their siblings lives, also had a significant impact on anxiety. Type of disability, severity of disabilities, comorbidities, behavior problems, age, sex and family of the individual with ASD also had a significant impact on predicting whether NT siblings were at risk of increased levels of anxiety. Lastly, perceptions of parental health, relationship and availability of supports also predicted anxiety in NT siblings (Marquis, Hayes & McGrail, 2019).

Many factors contribute to the challenges faced by neurotypical siblings. However, these factors can result in both positive and negative attributes, as was found by Corsano et al. (2017). While growing up as the sibling of someone with Autism can result resiliency for neurotypical siblings, these experiences can also attribute to sibling

disdain, challenges with friendship, and even lead to feelings of persecution for their experiences, as well as fear of future outcomes (Corsano et al., 2017). Siblings often feel as though they have dual roles within the family as both sibling, son or daughter, and caregiver to their sibling with Autism (Diener et al., 2015). According to Diener et al. (2015), these feelings often go invalidated by their parents, who perceive the sibling's roles as less complicated.

At times, NT siblings may even feel as though they are part of their sibling's therapy. A study by Sheikh, Patino & Cengher (2019) examined the benefits of parents using their neurotypical children as role models for their child with Autism. For example, when neurotypical siblings model prosocial behaviors such as sharing, using social manners and talking politely, the child with Autism is more likely to show these behaviors. It is possible that NT siblings who enact these interventions with their sibling and parents may inadvertently feel as though they are a tool for their parents to support their sibling with Autism, even if the intent is positive.

The role of siblings often changes overtime; moving from one of caregiving, teacher and parental support to taking over decision responsibility and advocacy as siblings and the person with Autism enter later adulthood (Rossetti & Hall, 2015). Siblings often experience conflicting feelings toward their sibling(s) with Autism, including guilt, shame, joy and thankfulness (Hall & Rossetti, 2018). Siblings often feel responsible for their sibling with Autism not only for being a role model and in supporting their parents, but as they age, they also feel responsible to ensure that their sibling has a good quality of life (Hall & Rossetti, 2018). Despite their ongoing conflicting feelings and increased sense of responsibility towards their sibling with

Autism, these neurotypical siblings do not often seek help or support, and little support other than online forums are offered to them (Dansby et al., 2018). An analysis of these online forums also show that these siblings are often seeking validation for their unique experiences in family dynamics, seeking coping strategies for their stresses and more (Dansby et al, 2018).

While NT siblings tend to experience significant shifting of their roles in the lives of their sibling with ASD, it is not currently known how widely experienced the phenomena of siblings role shifting is. The majority of the studies mentioned were conducted via qualitative analysis with a small group, ranging from 8 to almost 80 participants (eg. Carsano et al., 2017; Hall & Rossetti, 2018; Rosetti & Hall, 2015). Little research exists on how these stressors and experience may contribute to or correlate with sibling levels of depression and anxiety.

Social and Psychological Functioning in NT Siblings

Stresses experienced by the neurotypical siblings of a person with Autism range greatly from family to family, as does the degree to which the individual with Autism's symptoms are experienced. When the individual with Autism experiences more severe and intense needs, such as aggressive or maladaptive social behaviors, these tend to have a significant impact on the neurotypical sibling (Yacoub et al., 2018). Specifically, these siblings may have stunted empathy development, a sense that their needs are less important than their siblings with Autism needs, and a feeling that they need to be perfect as to not cause additional disturbances in the household (Yacoub et al., 2018). This stress tends to become deeply internalized, however. Shivers, McGregor & Hough (2019) found that neurotypical siblings of a person with Autism perceived their own social support and

behavior problems as being much more serious than the parents, teachers or peers of the person with Autism. This is evidence that these people feel the challenges of their sibling with Autism very deeply, and that it affects them tremendously.

The stress that neurotypical siblings internalize may lead to poorer outcomes for their functioning. Shivers, Jackson & McGregor (2019) conducted a meta-analysis on sixty-nine studies and found that siblings tend to have challenges with social functioning, internalized beliefs, adjustment challenges, coping difficulties and general functioning deficits related to internalizing their stresses. This meta-analysis, which included 69 independent studies, showed that neurotypical siblings had a 1.3 to 2.0 times reduction in general functioning (Shivers, Jackson & McGregor, 2019). It should be noted that the siblings with disabilities in the studies included in this meta-analysis were not limited to autism, but also included Down Syndrome, learning disabilities and physical illness/disabilities. However, their findings confirmed the research by Walton (2016), which also concluded that male siblings tend to have more social and adjustment problems, which is also exacerbated by being younger than their sibling with Autism, having lower family socioeconomic status and more behavioral problems in the sibling with Autism.

Neurotypical siblings of an individual with Autism experience a great level of stress, isolation and interfamily dysfunction which may ultimately affect not only their performance in many areas of life, but also their cognitive abilities. Studies have shown that siblings of children with Autism, developmental language delay (DLD) and mental retardation are at a higher risk of being diagnosed with a pervasive developmental disorder (PDD) (Pilowsky et al., 2007). Although siblings of children with Autism were

at lower risk of receiving a diagnosis of PDD than siblings of children with mental retardation or DLD, the risk is still higher than that of the general population, showing the propensity for genetic factors in general cognitive functioning. Similarly, Gizzonio et al. (2014) found that siblings of children with Autism, while scoring on the Weschler Intelligence Scales (WAIS) similarly overall to population norms, shared the cognitive profiles of their siblings with Autism. That is, they shared cognitive functioning fluctuations as strengths/weaknesses to their siblings with Autism. Gizzonio and colleagues concluded that there may be a genetic predisposition to a phenotype that is generally associated with Autism (2014). Lastly, a study done by Walton & Ingersoll (2015) found that emotional and cognitive adjustment, a key feature of cognitive functioning, differs in older male siblings of a person with Autism than from the general public. That is, their ability to adjust or control their thinking and emotions are compromised as compared to their peers.

While the older males showed less general aggression, they were also more avoidant and less relationally involved than the control group, which was also exacerbated by family stressors. Conversely, typically-developing sisters of a person with Autism tend to show the least difficulty with displaying challenging behaviors, especially when the behaviors of the sibling with Autism are less severe (Tomeny et al., 2016). This was an especially interesting finding as the researchers were comparing married to unmarried parents and their children's outcomes. They concluded that married couples tended to have fewer challenging behaviors with NT siblings than unmarried, except for sisters when challenging behaviors in the sibling with ASD were low (Tomeny et al., 2016). That is, while overall, the outcomes were worse for siblings when the parents were

unmarried (single or divorced) than if the parents were married, the effects did not apply as strongly for sisters when challenging behaviors of the child with Autism were low.

Siblings of children with Autism may face a myriad of challenges and may thus have differing perspectives and experiences from their peers. One way in which these siblings' experiences may differ from their peers is in their relationships and perceptions of their relationships with their parents. For example, neurotypical siblings of a child with a disability were found to have more externalizing and internalizing behavior problems associated with feeling as though their parents preferred their disabled sibling to them (Wolf et al., 1998).

Temperament is also a personality factor to consider in terms of sibling outcomes. Between the relationship of a neurotypical sibling and a sibling with Autism, temperament was found to be related to the quality of the relationships, and thus the outcomes for each sibling (Rivers & Stoneman, 2008). Specifically, the quality of persistence seems to predict more neurotypical sibling involvement and quality of relationship over other temperament qualities (2008). Similar to the findings of Wolf and Colleagues (1998), Rivers & Stoneman (2008) also found that differential parental treatment was also a mediating factor, often resulting in poorer outcomes for neurotypical siblings.

Sibling quality of relationship as a mediating factor in outcomes has been a widely studied topic, as can be seen. For example, neurotypical sibling's quality of relationship was found to be directly related to the adjustment of the neurotypical sibling (Jones et al., 2019). Specifically, when the sibling with Autism has more pronounced behavioral challenges, their relationship is more strained with their neurotypical sibling,

and this strained relationship is related to more challenges with adjustment in the neurotypical sibling (Jones et al., 2019). This research is supported by the prior research of Tomeny, Ellis & Colleagues (2017), who found that, inversely, positive sibling relationships between neurotypical and siblings with Autism are correlated with positive outcomes such as less stress and depression. However, these relationships were less likely to be positive, which means that fewer neurotypical siblings experience these relationship benefits as does the general population (Tomeny, Ellis et al., 2017).

Sibling Parentification

A common theme in much of the literature surrounding siblings of a child with Autism is the concept of parentification, although little research exists that specifically examines parentification in neurotypical siblings. Parentification is the concept that siblings or other family members take on more caregiving and parental roles than they would typically have in their family roles (Nuttall, Coberly & Diesel, 2018). Parentification is a factor in the examination of family dynamics that may change with the presence of a child with Autism, which is typically shown as a negative factor for neurotypical siblings (eg. Laghi et al., 2018).

Often, parentification is viewed as detrimental to neurotypical children; it is viewed as something that deters from their adolescent experiences and puts unnecessary and unhealthy responsibilities on them (Borchet et al., 2020). However, Borchet and colleagues (2020) outlined some positive outcomes that may come from parentification roles in neurotypical siblings, such as increased self-esteem, more mature views of relationships and increased coping skills.

Parentification of neurotypical siblings may not be limited to parental responsibility towards their sibling with autism. Many neurotypical children come to provide parental-type care for their own parents as they see them needing help, referred to as “parent-focused parentification” versus “sibling-focused parentification” (Nuttall, Coberly & Diesel, 2018, p. 1200). That is, some neurotypical siblings of a person with Autism may focus their caregiving on caring for their parent, and ensuring that their parent is taken care of, which is parent-focused parentification, as opposed to focusing their caregiving on the wellbeing of their siblings with ASD, which would be sibling-focused parentification (Nuttall, Coberly & Diesel, 2018). In fact, the study conducted by Nuttall, Coberly & Diesel (2018) found that neurotypical siblings are more likely to engage in parent-focused parentification than they are sibling-focused parentification at nearly double rates. The authors also noted that those who engaged in parent-focused parentification were also more likely to be goal-oriented in their future parenting choices, which was considered to be a positive attribute by participants. That is, neurotypical siblings who engaged in parent-focused parentification were more likely to make decisions on how they wish to parent in the future based on their experiences, as well as having plans to care for their sibling with Autism in the future. The authors conclude that while parentification has both positive and negative features for neurotypical siblings, it seems to cross typical parent-child boundaries either way. It should be noted that this study was conducted in a college-age sample group and did not include adolescent participants. However, these studies confirm earlier research that found that even neurotypical adolescent siblings tend to be more worried about the future than their peers without a sibling with Autism (Bågenholm & Gillberg, 1991).

The experience of parent-focused parentification was also examined by Tomeny, Barry et al. (2017), while examining the effects and roles of social supports for these neurotypical siblings. They found that siblings who engaged in parent-focused parentification who also lacked positive social supports (friends, siblings, mentors, etc.) experienced much higher levels of distress than those who had such social supports. This is especially important to note as parentification may naturally lead to less time spent with social supports, as there may be feelings of responsibility and guilt being away from the family in case a need arises (Borchet et al., 2020). Given this study, there may be a cyclical nature to the distress experienced in parentification; as siblings engage in more parentification, they disengage from social supports, which may lead to higher levels of distress.

Diathesis-Stress Model of Sibling Effects

Witnessing and experiencing frequent challenging behaviors from a sibling with Autism can lead to feelings of hyperarousal and fear of isolation and anxiety in the neurotypical sibling, which also contributes to increased parentification behaviors to offset these fears and anxieties (Yacoub et al., 2018). When siblings with Autism display more aberrant behaviors, the neurotypical siblings may also be more inclined to have their own behavior challenges, especially when the sibling with Autism is a male (Hastings, 2007). Hastings (2007) postulated that this may be due to the attention diversion of parents to the sibling with Autism or may be a coping mechanism for their internal stress. Orsmond & Seltzer (2009) agree with this theory and argue that a significant amount of the outcomes witnessed in neurotypical siblings can be attributed to the diathesis-stress model; environmental stressors lead to behaviors/reactions, which

shape the individual's adjustment and personality. According to some studies, neurotypical sisters are more likely to develop internalizing behaviors and problems, such as anxiety and depression, while neurotypical brothers demonstrate greater externalizing behaviors (getting into fights, physical aggression, property destruction, yelling, etc.) (Esfahani et al., 2018).

Until the last decade, few resources were available to siblings to help them cope and adjust to life as the sibling of a person with Autism. Research has only recently begun to look at the efficaciousness of both individual and group supports to help siblings normalize their experience, learn to process their experiences, cope, and gain camaraderie to prevent isolation (Tudor & Lerner, 2015). Based on the limited research on effects of being an adolescent sibling, it is not surprising that research into sibling supports is even more limited. However, the literature that does exist shows promising results for sibling adjustment and mental health improvements (Tudor & Lerner, 2015).

Effects on Adolescent Siblings

As can be seen, neurotypical siblings of a person with Autism can have a wide range of experiences, both positive and negative. While most research is geared towards the general effects of siblings psychological, emotional, and social functioning as a whole, some research has targeted the experiences of adolescent siblings.

Research on sibling and family dynamics when a child with Autism is present in the family has been focused largely on parent views and parent attention impacts on the family unit (Schuntermann, 2007). Adolescents can be negatively impacted by a variety of factors when they have a sibling with Autism, such as lack of parent attention, evidence of marital stress (parents fighting, stonewalling, etc.), and feeling like their

parent prefers their sibling with Autism (Schuntermann, 2007). However, as described by Schuntermann (2007), while these factors may be detrimental in the moment and may lead to distress, outcomes vary; many of these adolescents become very well adjusted and may actually develop stronger coping skills and resiliency than their non-autism sibling counterparts due to their experiences (Macks & Reeves, 2007).

One of the major factors that contributes to how well a neurotypical sibling adjusts is the behaviors displayed by the sibling with Autism (Yacoub et al., 2018). When siblings with Autism display socially aberrant or aggressive behaviors, neurotypical siblings often experience embarrassment and feelings of isolation from their peers, which is especially pronounced when the neurotypical sibling is younger than the individual with Autism (Yacoub et al., 2018).

Adult Sibling Outcomes

Since research into Autism has started to expand exponentially during the last several decades, research on outcomes in neurotypical sibling's outcomes has also begun to emerge, as was previously previewed. Specifically, over the last several years, research into adult outcomes and contributing factors therein has occurred but has for the most part looked at broad themes and has mostly included more diagnoses besides solely ASD.

A broad survey conducted in 2015 on adult sibling outcomes looked at cognitive, behavioral, social and emotional factors relating to their Autistic sibling. They found that, overall, most adults were fairly well adjusted as compared to their peers and about 20% of participants displayed what the authors referred to a "Broader Autism Phenotype," or "BAP," although overall testing within the average range for cognitive skills (Howling et al., 2015, p. 707). They defined BAP as displaying social, behavioral or cognitive traits

generally attributed to Autism. Of note, they subsequently found that these adults who fit in the BAP category were also statistically more likely to have higher anxiety and depression scores than those they deemed as being “unaffected” by their Autistic sibling (Howling et al., 2015, P. 712). Their findings spark further questions on the effects of heredity, genetic influences and environmental factors that contribute to adult sibling outcomes. It should be noted that this particular study had a fairly small sample size (N = 87) and was overall relatively young (average age was 39), which may not necessarily represent longitudinal outcomes for adult siblings and may not take cohort effects into account with different generational groups.

Some recent research on adult siblings also correlates well with research on adolescent siblings. For example, Moss and colleagues (2019) found that negative outcomes with adult siblings were largely due to coping with their ASD siblings’ behavioral challenges, which matches the findings in adolescents by Orsmond & Seltzer (2009). However, Moss et al. (2019) also attributed much of the negative adult outcomes and perceptions to be due to familial relationship strains and the negative effects their Autistic sibling had on their social life.

Additionally, adult siblings also have the strain of worry about future care for their Autistic family member (Moss et al., 2019). That is, a common question that arises in households with an adult with Autism is who will care for them once mom and dad have passed away? Questions of legal guardianship, care, where they will live, if they will live with a family member or in a group home, who will manage their finances, all contribute to the fear and anxiety experienced by many adult siblings (Noonan et al., 2018). All the while, many of the siblings continue to feel the same feelings of isolation,

preference and invisibility within the family system regarding their parents (Noonan et al., 2018).

While the experiences vary for neurotypical siblings regardless of age, it is clear that they face unique challenges which may be detrimental to their outcomes and family relationships. Siblings face social isolation, increased feelings of family and caregiving responsibilities which lead to parent-focused parentification and sibling-focused parentification which further isolate them from their peers and cause significant stress. While these stressors and unique senses of responsibility may have benefits such as increased adjustment and coping, it can also result in higher likelihoods of experiencing anxiety and depression.

When more children are part of the family unit, these effects may become even more complex. Birth order may play a role in the health and function of the family unit for both the individual who has ASD, as well as their neurotypical siblings (Sprey, 1998).

Birth Order Effects

Birth order is believed to effect personality, temperament and may potentially even predict mental health diagnoses, although the research is somewhat conflicted in this area. Publishing in 1994, Feehan, et al. began a longitudinal study in 1972. They searched for help-seeking behaviors for psychotic symptoms in relation to birth order. While they did not find any significant correlation, they concluded that first-born females were at the greatest risk of having an internalizing disorder. Between the beginning of Feehan and colleague's study to publication, Kelnter, McIntyre & Gee (1986) looked at whether birth order effects existed in second-generation alcoholics. They found that middle-born born and later-born children are at greater risk

for depression and psychopathology. Between these two studies, a clear picture began to emerge: birth order should be examined as a factor in a person's psychological health. However, very little detail therein was thus far noted.

While Keltner, McIntyre & Gee's findings did not match the researcher's original hypotheses, their research spurred a wider flurry of research into birth order, intensified by the findings of Feehan, et al. (1994). Among these studies was Richter, et al. (1997). They studied birth order and psychopathology in relation to childrearing styles. They found that middle children were at higher risk of psychiatric challenges related to "unfavorable" parenting styles (1997). Again, this continued to spur the discussion regarding effects of birth order as well as familial size, demonstrating potential for environmental factors *in conjunction* with birth order to play a role in the risk of psychopathology.

During this same period, one of the most famous and most cited books on the topic of birth order was written and published: *The New Birth Order Book: Why You Are the Way You Are* (Leman & Leman, 1998). Dr. Leman's book examines personality traits of each birth position (first, middle, and last) as well as noting variables which may explain why some people do not fit the typical roles he postulates, such as genders, age gaps, religious upbringing, culture, and more. While Dr. Leman has become the forefront spokesman on birth order since his publication, he is not without his critics. Ratledge sought to dispel the "myths" of birth order presented by Leman and essentially argued that Leman's generalizations were too broad (2013). Ratledge argued that parenting style and practices have a more significant impact on individual outcomes in personality than does birth order. It may be argued that much of Leman's theories on birth order are

anecdotal, and may even utilize the Barnum effect, which is the phenomenon wherein one may believe generalizations which apply to a large swathe of people may be applied specifically about themselves (Ungvarsky, 2019).

Since Leman's (1998) publication, research into the effects of birth order has continued around the world. In 2015, Ghaderi, Fijan and Hamedani conducted an interesting experiment, examining how birth order may affect a child's conduct in a dental office, a well-known location of childhood anxiety. They found that children with no siblings exhibited much more anxious behaviors, and middle children tended to be the most cooperative. Their findings provide a foundation for several psychopathological inferences. This could provide some insight into different psychopathological risk for children in these birth order positions, such as anxiety and even a lack of psychopathology. However, based on this study alone, only inferences can be made.

Delving deeper into sibship and psychopathology, Easey, et al. (2019) studied the associations between birth order and suicidality. They found that those who were earlier born had more suicidal ideation which was highly correlated with psychiatric disorders. However, like previous research on parental influence, they also found positive mediation between birth order and suicidal ideation, as well as psychoticism with parental factors. That is, they found that when a father was absent and/or when a mother was depressed, there was an 8% increase in likelihood of suicidality overall, and 12% increase among those with a psychiatric diagnosis. This was not evident to the extent they had hypothesized, however. Their study was replicated by Jackson (2018), who confirmed the previous findings and furthermore found that only-children are at the

highest risk of suicidal ideation. This may also have implications for rates of depression in differing birth orders, as well as the effects of parental absence.

Middle children are believed to be more attention-seeking since they are “invisible children” (Leman & Leman, 1998). German researchers Kirkaldy, Richardson-Vejlgaard and Siefen (2009) appear to concur with this finding. They found that middle children, especially women, are at the highest risk of self-injury, which is traditionally considered a cry for help, attention or both. Lawson and Mace (2010) found that older siblings tend to have more mental health challenges, while being a younger sibling seems to be a protective factor. Similarly, Japanese researchers Liu, et al. (2015) found that a child with an older brother was at a reduced risk of mental health challenges. They found this was especially true for girls, and that only children were at the highest risk.

Spanish researchers Carballo, et al. (2013) studied over 16,000 cases between 1980 and 2008 for their longitudinal study on birth order and childhood mental disorders. They found that first-borns and only children were at the highest risk of receiving a diagnosis, with a greater number of siblings being a risk factor for receiving a mental health diagnosis. They also found that middle children were at the highest risk of being diagnosed with ADHD. To tie these findings together, Zain, et al. (2015) studied 100 US psychiatric inpatients and found that fourth-born siblings were at the highest risk of receiving a diagnosis, with firstborn siblings at the second-highest risk. These findings seem to confirm Carballo, et al. (2013) in that those with more older siblings are at a more reduced risk of mental health challenges.

While the above studies identified some of the stronger correlations made thus far between birth order and psychopathology, they are very narrow in terms of diagnostic scope, environment, and do not address many diagnostic categories. In addition, most of the more recent studies were not conducted in the United States. As cultural norms and environmental factors may be extremely diverse between the countries in which these studies were conducted, further research is needed to explore birth order in conjunction with psychopathology as related to the typical American family.

As can be seen, significant research and query into the effects that birth order has on a persons' mental health has been a growing field of research. While research into birth order was emerging in the 1970s, Gates et al. studied its relationship to depression, anxiety and self-concept in children in 1988. Unlike following studies, Gates and colleagues found that first-borns appeared to be a significantly lower risk for anxiety than those later born (1988). However, as this study used a relatively small sample (404) in addition to studying various traits, it seems as though there could potentially have been confounding variables within their methodology.

After Gates, research into the connection on birth order effects remained largely untouched for the next decade, during which time Leman & Leman (1998) made their famous publication. However, that began to change near the late 2000s. In 2009, Pearson studied the phenomenon for her dissertation. She hypothesized that those first born, especially females, would be especially at high risk for anxiety, however, the results of her study showed no significant differences in birth order and anxiety, even with gender considered. However, the limited number of participants ($n = 56$) should be considered with these results. Shortly thereafter, Aminabadi and associates studied

anxiety in relation to birth order in a dental setting (as established in earlier research, a highly anxiety-invoking setting for children). They found that first born children were indeed at the second highest risk of developing anxiety in the dental setting, preceded by only children (Aminabadi et al., 2011).

Additional research began to occur throughout the world with the increase of internet survey options. In 2017, an online survey was conducted of over one-thousand Polish and German children to see if birth order and emotional distress. Similar to Pearson, they found no significant difference in birth order, except for that of only-children as compared to those with siblings (Hardt et al., 2017). Finally, getting more specific to the question at hand, Callaway wrote her theses on the very issue. Again, Callaway concluded based on her research that birth order and anxiety did not appear to be correlated or predictive (Callaway, 2018).

Research into the experiences and functionality of neurotypical siblings of a person with Autism has been somewhat sporadic, especially in regards to birth order, and has been experiential in nature (that is, it has mostly looked for emerging themes as opposed to looking at specific factors, such as Walton, 2016; Tomeny et al., 2017; Yilmaz & Kara, 2018; Wright & Benigno, 2019). While a variety of psychological challenges among NT siblings have been explored in the literature, the presence of internalizing behaviors (anxiety, depression, stress, etc.) was thematic throughout the present literature. Other psychiatric disorders or expressive features (aggression, acting out, substance abuse, etc.), which while present to a lesser degree, were not as prevalent through the literature as internalizing behavior. However, studies continue to be limited

in their scope, even on internalizing behaviors, and conclusive data on sibship effects for NT individuals with a sibling with Autism has yet to be found.

Anxiety and Depression in Neurotypical Siblings

Research has shown that the challenges faced by neurotypical siblings and the emerging nature of both family psychoeducation and supports may lead to higher rates of maladaptive internalizing behaviors. Internalizing behaviors are most commonly expressed in anxiety and/or depression (Esfahani et al., 2018). The likelihood of experiencing depression symptoms and anxiety symptoms at the same time is high. Studies have shown that the prevalence of adult Americans experiencing both anxiety and depression symptoms is between 73% and 90% (Gorman, 1996; Moffitt et al., 2007; Orsmond & Seltzer, 2009; Salcedo, 2018). Hence, separating the two in regard to mental health could be challenging, and it is more beneficial to analyze them concurrently. It should not, then, be surprising that research has focused primarily on either anxiety or depression in neurotypical siblings, but little on the co-morbidity of anxiety and depression, or the intercomparison therein.

Anxiety Among NT Siblings

Although some of the aspects of neurotypical siblings' increased anxiety has already been briefly mentioned, it is worth noting that research into the specific differences in the anxiety levels of neurotypical siblings of Autistic individuals is sparse at best. Even earlier studies that revealed a trend in increased anxiety, particularly surrounding future-oriented planning, tends to have small samples and have not been replicated (Bågenholm & Gillberg, 1991; Lee & Burke, 2020). A 2017 study suggests that siblings of people with Autism are at higher risk of anxiety than siblings of

individuals with other developmental disabilities, such as Down Syndrome (Shivers, McGregor & Hough, 2017). This is especially noteworthy when considering that previous research has shown that siblings of an individual with an intellectual disability of any sort are at higher risk of anxiety (Shivers et al., 2013; Tomeny, Ellis et al., 2017). In fact, recent studies suggest that anxiety in siblings of an Autistic person may be as much as 250% more likely to qualify for an anxiety diagnosis than the general population, including generalized anxiety disorder, obsessive compulsive disorder and phobia disorders (Nimmo-Smith et al., 2020).

Throughout the research over the last several decades, a clear theme with sibling anxiety relating to Autism is that the relationship quality of the neurotypical sibling and the sibling with Autism is one of the largest predictors of the level of anxiety experienced by the neurotypical sibling (Tomeny, Ellis et al., 2017; Shivers et al., 2013; Pollard, et al., 2013). These studies all show a negative correlation between relationship quality and sibling anxiety; when the Autistic sibling and the neurotypical sibling have a higher quality relationship (closeness), the neurotypical sibling is likely to be less anxious. This also seems to have a reciprocal relationship. Other studies have shown that when neurotypical siblings are closer to their Autistic siblings, the behaviors displayed by the Autistic sibling are likely to be less severe and challenging, which in turn can lead to a higher relationship quality (Tomeny, Ellis et al., 2017; Hastings & Petalas, 2014). There is clearly a circular relationship in types of displayed behaviors by the sibling with Autism, quality of relationship and anxiety in the neurotypical sibling.

Research into the specific contributing factors for neurotypical sibling anxiety, outside of sibling relationship quality, is extremely sparse. One study, however, showed

that older siblings (older than the individual with Autism) showed lower rates of anxiety than younger siblings (Montes, 2018). These authors suggest that not only may birth order play a role in these found effects, but that having a developed identity prior to the introduction of Autism into the family unit likely plays a role.

Whatever the cause, root or correlation, one thing that is clear is that neurotypical siblings of an Autistic person are more likely to experience symptoms of anxiety than their peers. While the research into their experiences may be currently limited and often with small sample sizes, the findings of higher rates of anxiety seem to be consistent in this unique population.

Depression Among NT Siblings

As the risk of anxiety is higher in neurotypical siblings, and studies have shown the likelihood of internalizing behaviors is also higher in these siblings (Esfahani et al., 2018), rates of depression in neurotypical siblings are also likely to be higher in these individuals than their peers. However, some studies have shown that these siblings are not at higher risk of depression than their peers (Rodgers et al., 2016), which seems to be contested by other studies (Orsmond & Seltzer, 2009). Contributing factors to depression are in many ways similar to that of anxiety, but some studies have shown some specific differences in potential moderating and mediating factors.

Although studies have shown mixed results on the prevalence and effects of anxiety in NT siblings, neurotypical siblings of an Autistic person may be likely to have higher rates of depression. Similar to anxiety, however, studies on depression in NT siblings has also shown mixed results. Some research has shown that depressive symptoms in NT siblings of a person with Autism may be exacerbated when there is a

lack of quality social support (Lovell & Wetherell, 2016). In addition to social supports, when parents show more symptoms of anxiety, the neurotypical siblings are also more likely to develop depressive symptoms (Koukouriki, Soulis & Andreaoulakis, 2020).

Most studies related to depressive symptoms in neurotypical siblings are not isolated to solely depression but examine both depression and anxiety given the high likelihood of comorbidity and homogeneity. Findings in this arena have been mixed. For example, O'Neill & Murray (2016a) found that siblings were more likely to have depressive symptoms than anxious symptoms. While this study has not been replicated, its findings are largely opposed by other studies.

Early research into the family experience of people with Autism found that both parents and siblings experience higher rates of social phobias (anxiety) and depression than the general population does (Lainhart, 1999). These findings have since been seen in recent studies, such as by O'Neil & Murray (2016a), who found that rates of anxiety and depression among neurotypical siblings are significantly higher than the general population.

As it has been widely accepted by the developmental disabilities community that family members are more likely to experience higher rates of anxiety and depression, some studies have sought to examine the many factors that relate to this, rather than simply confirming or denying these prevalence rates (Murray & O'Neill, 2019), such as parental effects (Girli, 2018), family dynamics (Herrema et al., 2017) and other family psychopathology (Pilowsky et al., 2007). For example, a 2019 study by Murray & O'Neill found that, within their study sample, rates of both anxiety and depression rates were higher in NT siblings than in control samples and also found that this was

seemingly related to personality traits such as neuroticism and extraversion. Higher neuroticism and extroversion had an especially high correlation with rates of depression in their sample. Other research has similarly shown that temperament can be either a contributor or protective factor against depression in siblings (Bitsika et al., 2015). While both brothers and sisters of a person with Autism at higher risk of having anxiety and/or depressive symptoms, sisters are especially at higher risk of developing depression (Bitsika et al., 2015). However, these findings may not be surprising given that women are more statistically likely to experience symptoms of depression than men in the general population (Villarroel & Terlizzi, 2019).

Supports for Siblings

It may not be surprising given the unique nature of these neurotypical siblings' experiences that they are more likely than their average peer to seek help and support for their experiences. Siblings who report feeling that they have robust social supports tend to report fewer problems with both their own mental health and within the home, but siblings reporting such robust supports seem to be few (Tomeny et al., 2019). In the age of blogs and internet searches, it may not be surprising that many such siblings seek support from others online. A study done by Dansby et al. (2018) examined forums for siblings of people with Autism and found that many were seeking coping strategies from others as well as a general sense of validation and comradery.

Some recent studies have focused on educating parents on how to support all their children while paying special attention to the social, emotional and relational needs of their neurotypical children (Tsao, Davenport & Schmeige, 2012). Education of parents on promoting healthy family dynamics has been supported by research into the efficacy of

Family Systems Therapy (FST), which has been proven to improve individual family member mental health (Wright & Benigno, 2019). Similarly, Lobato & Kao (2002) advocated for sibling involvement in therapies and knowledge with their sibling to help promote connectedness with their Autistic sibling, which led to increased overall quality of family satisfaction.

Given the recent realization that siblings have been largely left out of the picture in Autism supports, some pilot programs have been enacted to provide such supports. As such, studies have begun to examine the efficacy of these programs. Thus far, the most popular form of formal supports for neurotypical siblings has been group therapy/supports, which, while having overall more positive outcomes for participants, has shown mixed results in efficacy (Tudor & Lerner, 2015; Thomas, Reddy & Sagar, 2016). Similarly, psychoeducation groups have been proven to be efficacious and even shown to reduce emotional and behavioral challenges by neurotypical siblings, as compared to control groups (who did not participate in support groups) (Brouzos et al., 2017).

Fortunately, as the research into the nature of Autism and its effects on families has increased, so has the awareness for supports for all members of the affected family. A pilot program was developed by the University of Illinois to support neurotypical adult siblings of an individual with an intellectual and developmental disability (IDD), which includes Autism Spectrum Disorder (Burke et al., 2020). They found through their pilot program that adult siblings who engaged in the program felt more empowered, connected and felt as though they had more resources to handle their experiences (Burke et al.,

2020). This is evidence of the need for adult sibling supports and the efficaciousness of normalizing their experiences.

Purpose of the Present Study

Research on the experiences of people with ASD and their parents has been underway since the 1980s and has been increasing in recent decades as awareness of autism has increased. The experiences of parents has been closely studied, as they are the primary caregivers. Parents are likely to experience isolation, anxiety, depression, higher rates of divorce and fracturing of the family due to the presence of Autism in their family.

While parental experiences have been well-studied, there remains a large gap in the literature on the experiences of neurotypical siblings of someone with Autism has been a large gap in research. Studies into both child and adult NT sibling' experiences are beginning to emerge, with common themes of support-seeking and relationship quality emerging as key factors in sibling outcomes. While research is still emerging in this area, the vast majority of the current studies show that neurotypical siblings are at a much higher risk of developing symptoms depression and anxiety than their peers.

As the research into the experiences and mental health of neurotypical siblings of an Autistic person is emerging and limited, the present study aims to add to the breadth of the currently available literature. Specifically, there is little research that investigates the prevalence of anxiety and depression among NT siblings of an Autistic person. Further research on prevalence and rates of anxiety and depression may help inform future research on examining factors that contribute to these mental health conditions. In turn, knowing these factors can help shape the supports available to siblings and their families, and inform educators and professionals in how to best support and validate the

experiences of neurotypical siblings of a person with Autism. The present study will aim to examine the prevalence rates of anxiety and depression, as well as whether sibship, age distance and gender moderates the rates of anxiety and/or depression to inform and contribute to future research into such supports and education.

Research Questions/Hypotheses

Given the current and previous research into families of individuals with ASD and lack of research regarding siblings, three primary research questions emerged:

Research Question 1

What is the prevalence of generalized anxiety disorder symptoms and/or depression in a sample of adult siblings of an individual with Autism Spectrum Disorder (ASD)? As the literature has been largely void of information pertaining to the prevalence rates of anxiety and/or depression specific to siblings of someone with ASD, this question is exploratory in nature and no hypothesis is offered. Past and recent research on siblings largely conclude that neurotypical siblings tend to experience symptoms of anxiety and depression given their social and familial isolation, worry about the future, parentification and added senses of responsibility, however, statistical prevalence rates have not yet been explored. The present research question seeks to explore these rates in a given sample. Anxiety and depression will be measured and evaluated as separate variables.

Research Question 2

Does being an older or younger sibling of the individual with ASD relate to the likelihood of generalized anxiety disorder symptoms and depression? The hypothesis is that individuals younger than their sibling with ASD will present with higher rates of

anxiety and/or depression than older adult siblings. As the research has shown that being older than the sibling with Autism is a protective factor, it is likely that younger siblings of individuals with ASD are more susceptible to mental health disorders than the general population, and likely the closer in age they are to the individual with ASD, the more potent their diagnosis may be. This may be due to the lack of parental attention that they experience due to the needs of their older sibling with Autism. These younger siblings may also take on more caregiving rolls to support the family structure and parents than the average person their age might, which could affect their social and emotional growth. As such, it is hypothesized that younger siblings of a person with ASD will be at a higher risk to develop depression and/or anxiety than older sibling of a person with ASD.

Research Question 3

Does age distance from the individual of ASD affect the likelihood of generalized anxiety disorder symptoms and/or depression symptoms? Research on effects of age distance does not currently exist, and if significant effects in age distance is found, it may contribute to future research and may have clinical implications. No hypothesis is posited for this research question as there is no research to support a hypothesis at this time. This question will be exploratory in nature. As it is hypothesized that being a younger sibling than the individual with ASD, the question remains whether age distance is a factor in either potentiality of a internalizing disorder, or in severity. For example, is there a difference in the likelihood of receiving a diagnosis of anxiety/depression or in the severity of the diagnosis if one is two years younger than their sibling with ASD as opposed to four years? This research question seeks to understand whether there are any age distance effects in diagnostic potentiality and/or severity of diagnosis for the sibling

of the person with ASD. As the research also shows that older siblings tend to take on more responsibility for their younger siblings and in parentification, an alternative hypothesis is that older siblings may experience higher rates and/or severity of anxiety and/or depression symptoms.

Research Question 4

Does biological sex affect the rates of generalized anxiety disorder symptoms and/or depression in neurotypical siblings of a person with ASD in a given sample? The present study hypothesizes that female siblings will be at greater risk of generalized anxiety disorder and/or depression symptoms than male siblings. As the research has shown that females tend to be at higher risk of internalizing behaviors than males in general, as well as female siblings of people with autism engaging in more parentification.

Chapter 2

Methodology

The present study utilized a cross-sectional design, which is an empirically proven effective method to use specific time-referenced or current data to make predictions of outcomes (Levin, 2006). The present study sought to find the prevalence rates of anxiety and depression in adult siblings of a person with ASD in a given sample. Having a sibling with Autism will be a requirement for study participation. Further details about participation, subject protection, materials and measures are covered in the sections below.

Participants

Participants were over 18 years of age and were the self-reported sibling of someone who was professionally diagnosed with Autism Spectrum Disorder. Professional diagnoses of ASD were reported by the sibling/participant, but not confirmed by the researcher. Similarly, the kinship of the participants to an individual with ASD was also not corroborated. A total goal of 78 participants ($N = 76$) for the study was set based on an a priori. The survey was only available in English. While a question regarding geography was asked on the survey, no requirements for geographic location were a condition of participation. All participants identified as living in the United States of America.

An a priori power analysis was conducted using G*Power3 (Faul, Erdfelder, Lang, & Buchner, 2007) to test the exploratory questions. Parameters were set for a medium effect size ($f = .30$), and an error probability (alpha) of 95% ($p > .05$). Result showed that a total sample of 78 participants were required to achieve a power of .95 in

the largest analysis being conducted. Further information on power analysis for specific variables and exploratory questions can be found under Data Analysis.

Materials & Measures

A web-based survey was developed by the author utilizing established screeners designed to compare ASD sibling rates of anxiety and depression and was expected to take approximately 5-10 minutes to complete. The questionnaire was comprised of a total of 17-items (not including the consent) and had four sections; demographics, family/sibling information, the anxiety screener and the depression screener. Additionally, basic demographic and familial information were collected.

For analysis purposes, the anxiety and depression rates were descriptively compared to the national averages for anxiety and depression. According to the National Institute of Mental Health, the national rates of Major Depression in 2017 (the most recent comprehensive survey completed) was 7.1% for adults (8.7% for females, 5.3% for males) (NIMH, 2019). This was measured by whether the individual had experienced at least one major depressive episode in the previous year. Additionally, adults ages 18-25 were at the highest risk, with a prevalence rate of 13.1%. Similarly, adults of two or more races were also at higher risk at 11.3%. Anxiety has an overall prevalence of 15.6% in US Adults (Terlizzi & Villarroel, 2019). Among adults, those experiencing mild symptoms were 9.5%, moderate was 3.4% and severe anxiety was 2.7%. Similar to depression, adults ages 18-29 were at the highest risk of anxiety at 19.5%, compared to those above the age of 65 at 11.2%.

Anxiety level was measured using the Generalized Anxiety Disorder 7-item Scale (GAD-7; Appendix C). The GAD-7 is a commonly used anxiety screener which has

been found to be valid ($r = .69-.90$, $p = < 0.01$) and reliable ($\alpha = .88$) (Johnson et al., 2019). The GAD-7 was also found to have sensitivity of 89% and specificity of 82%, as well as having strong external validity when compared with other established scales (Spitzer et al., 2006). The GAD-7 uses a 4-point Likert scale (0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day) to measure whether the participant has experienced the physical, cognitive or emotional symptoms of anxiety over the previous 2 weeks, and yields a score in the range of 0-21. Scores of 0-4 correlate to minimal anxiety, 5-9 mild anxiety, 10-14 moderate anxiety and 15-21 extreme anxiety.

Depression was measured using the Center for Epidemiological Studies Depression Scale (CES-D; Appendix D). The CES-D has been found to be a valid and reliable ($\alpha = .85-.94$, $p < .05$) for varying populations (Mohebbi et al., 2017), 90% specific and 86% sensitive (Parikh et al., 1988). That is, the CES-D is able to measure depressive symptoms accurately while not measuring non-depressive symptoms. The CES-D is a 20-item self-report scale, such as item number 2, which states “I did not feel like eating; my appetite was poor.” Items are rated on a 4-point Likert scale. Raters report whether they experienced the identified emotional, cognitive and physical symptoms within the past week of taking the questionnaire. Reported scores are 0 (Rarely or None of the Time; Less than 1 Day), 1 (Some or Little of the Time; 1-2 Days), 2 Occasionally or a Moderate Amount of Time; 3-4 Days) and 4 (Most or All of the Time; 5-7 Days). Scores between 0 and 60 are possible. Scores of 16 or higher are considered to indicate “Mild to Moderate” depression, and scores of 21 and over are considered to indicate major depression and are clinically significant (Radloff, 1977).

Study Procedures

Upon approval from the Human Right Commission, participants were recruited from a variety of convenience samples from online social media platforms as well as students in the Northwest University's undergraduate and graduate programs and word-of-mouth recruitment. Data collection and survey administration was conducted using Qualtrics, a secure online data collection platform. Participation was anonymous and did not utilize any identifying information such as names, birth dates or addresses. Data collection and survey administration was conducted using Qualtrics, a secure online data collection platform. Collected data was analyzed using SPSS.

Data was collected using Qualtrics, a secure and encrypted online questionnaire program (Appendix B). Participants were presented with the consent for participation form, which included the risks and benefits to participation along with resources in the case the participant experienced distress while answering the survey questions (Appendix A). Upon consenting to participate, they were asked a series of basic non-identifying demographic questions. Then participants completed the Generalized Anxiety Disorder Questionnaire, 7 Question Form (GAD-7), followed by the Center for Epidemiological Depression Survey (CES-D). The study concluded with the option to enter their email to win the offered raffle of 1 of 4 \$25 Amazon gift cards (see Appendix E) or to skip the raffle and end the survey. After making their choice, the initial resources for any discomfort or distress caused by participation were reiterated, and they could then exit the survey and their scores were recorded.

The study survey and email raffle opened and closed in October of 2021. The 4 raffle winners were randomly selected, and 4 \$25 Amazon gift cards were sent to the

randomly selected emails directly from the Amazon website the day after the survey was closed.

Summary

The present study sought 78 adult participants who had a sibling with Autism and were ages 18 and over. Participants were found using a snowball method and were offered to participate in a gift card raffle with no other incentives for participation. All participants' privacy was protected and all were offered support for participation in case of distress. The survey was conducted using a secure and anonymous online questionnaire. The questionnaire was comprised of a consent form, basic demographics, sibling information, and the GAD-7 and CES-D. Anxiety was measured using the GAD-7, and depression was measured using the CES-D. These are validated and reliable measures for these variables. Data was analyzed using SPSS, and variable means compared using descriptive analytics and multivariate analyses of covariance (MANCOVA), which is discussed in chapter 3.

Chapter 3

Preparation of Data

All data was imported directly from the online Qualtrics survey into SPSS on a password-protected and encrypted computer. Several variables were coded for analysis. Variables for primary analyses (GAD-7 total scores, CES-D total scores and age distance) were found to have normal distributions and no skewedness. Standard residual analyses showed that the statistical requirements for normality were met across all examined variables.

Of the total participants who began the survey and answered at least 1 question, 11 participants were excluded as they did not complete the survey past their birth year despite being over 18 years of age. Additionally, 45 participants were excluded as they did not meet the participation criteria of having a sibling reportedly professionally diagnosed with Autism. Several variables were recoded and new variables were created. Ethnicity and Sibling types were coded from text entry to numeric codes. As all participants identified that they resided within the United States, their State of residence was coded as the two-letter code corresponding to their state, such as “WA” for Washington State. A new variable was created for the total GAD-7 scores in which the 7 questions from the GAD-7 were summed into a new variable titled “GAD7_TOTAL,” and the 16 questions included in the CES-D were summed into a new variable titled “CESD_Total.” These were the primary variables used for analysis. Age distance was computed as being either a positive or negative number, with those who were younger coded as a negative number. For example, a participant who rated that they were 4 years

younger than their sibling with ASD, had their age distance was coded as “-4.” All data was coded and analyzed using the Statistical Package for the Social Sciences (SPSS).

Analytic Strategy

The primary research questions were analyzed using coded variables. Research question 1 used descriptive statistics to analyze the prevalence of anxious and depressive symptoms across all valid participants. Research question 2, 3 and 4 used a multivariate analysis of variance (MANOVA) to analyze the between- and within-group differences of sibship (older and younger siblings), age distance and sex effects for anxiety and depression. All continuous variable demographics were run against the GAD7_TOTAL and CESD_TOTAL variables for potential correlations (such as age, number of siblings, etc.).

Participants

A total of 556 respondents were collected for the study. 3 participants were included in analyses regarding anxiety as they completed all sibship and GAD-7 questions but were not counted in depression analyses as they did not complete the CES-D questions. A total of 500 participants were used in the analysis of the study regarding anxiety (N = 500), and 497 used in analyses of research questions regarding depression (N = 497).

The average age of the studied population was 33 (range = 20-58). The participant pool included participants from 47 States within the United States. States that did not have any participants included Rhode Island, Hawaii and Montana. The largest representation was from Texas (N=68), Pennsylvania (N=46), California (N=35), Illinois (N=25), Missouri and Washington (N=21 each), and the remainder between 1-19

participants in each State. Household incomes also varied significantly, with the average median being \$30,000-\$59,000. Further demographics can be found in Table 1.

Table 1*Participant Demographics*

Baseline Characteristic	N	%
<i>Sex</i>		
Male	240	48
Female	256	51.2
Chose Not to Respond	4	0.8
<i>Ethnicity</i>		
White/European American	466	93.2
Hispanic/Latino	10	2
Multiple Ethnicities	6	1.2
Black/African American	5	1
American Indian/Alaska Native	5	1
Native Hawaiian/Pacific Islander	4	0.8
Asian	3	0.6
<i>Relationship Status</i>		
Married	180	36
Divorced	78	15.6
Separated	72	14.4
Widowed	62	12.4
Chose Not to Respond	1	0.2
<i>Education</i>		
< High School Diploma	8	1.6
High School Diploma or Equivalent	20	4
Some College, No Degree	73	14.6
Associates Degree	76	15.2
Professional Degree	28	5.6
Bachelor's Degree	98	19.6
Master's Degree	44	8.8
Doctorate Degree	40	8
Chose Not to Respond	114	22.8
<i>Employment</i>		
Management, Sale/Office	76	15.2
Service	71	14.2
Construction	47	9.4
Unemployed	45	9
Production/Transportation/Materials Moving	43	8.6
Government	41	8.2
Farming/Fishing/Forestry	39	7.8
Full-Time Student	36	7.2

Retired	24	4.8
Did Not Answer	2	0.4
<i>Income</i>		
< \$10,000	6	1.2%
\$10,000-\$29,999	94	18.8%
\$30,000-\$59,999	130	26.0%
\$60,000-\$89,999	115	23.0%
\$90,000-\$99,999	122	24.4%
\$100,000-\$149,999	19	3.8%
\$150,000 +	14	2.8%
Total Participants	500	100

Data Analysis

All participants were given a digital consent form prior to answering any research related questions. No in-person interviews were conducted, and no identifying information was asked outside of basic demographics. Some of the questions related to pain, feelings of anxiety, depression self-harm and substance use. These questions did not ask for further or specific details, but simply asked whether they have felt or have participated in those feelings or activities. While participants were asked whether they have a sibling with Autism Spectrum Disorder as well as their age difference from this sibling, no other questions pertaining to this relationship were asked in the present study. As some of these questions may have incurred distress, the local help-hotline was provided for immediate assistance for potential cases of life-threatening concerns or significant psychological/emotional stress. The American Psychological Association website was also provided for a directory of providers if the person wished to seek more long-term assistance.

Examined Variables

The examined variables in the present study were correlated with the research questions. The research questions are reiterated below, and the subsequent analysis method is stated for each.

Research Question 1

What is the prevalence of generalized anxiety disorder symptoms and/or depression in a sample of neurotypical siblings of an individual with Autism Spectrum Disorder (ASD)? The rates were deciphered by conducting a descriptive analysis within the collected sample population and those who score within a significant range on the GAD-7 and the CES-D (scores 10 and above for anxiety, and 16 and above for depression, respectively). As this question compared groups and was descriptive in nature, no power analysis was conducted on participant population size goals. When entered into SPSS, a new variable was created for total GAD-7 and total CES-D scores, and these scores were used to show the prevalence of internalizing disorder symptoms in the given population using descriptive statistics.

Research Question 2

Does being an older or younger sibling of the individual with ASD relate to the likelihood of generalized anxiety disorder symptoms and depression? A question on the Qualtrics survey asked if they are older or younger than their sibling with ASD, which separated the participants into the two groups which were used for analysis. Their birth order (older/younger) was used as the independent variable, with their anxiety and depression scores acting as the dependent variables (respectively). A Multivariate Analysis of Variation (MANOVA) was utilized to analyze any potential relationship

between birth order and participant's anxiety and depression scores. An A priori using G*Power was conducted to find a target population size for a MANOVA (within-groups) which will produce a power of at least 0.95 ($p = 0.05$), which yielded a total target sample size of 52 participants.

Research Question 3

Does age distance from the individual of Autism effect the likelihood of generalized anxiety disorder symptoms and/or depression symptoms? Participants were asked the year they were born and the year their sibling with Autism was born. Age distance was calculated as a separate variable in SPSS as the birth year of the sibling with ASD minus the birth year of the respondent. Older siblings had a negative age distance, with younger siblings having a positive age distance. (Example: Participant born in 1986, Sib with ASD born in 1991 = 5; Participate born in 1991 and ASD sib born in 1962 = -5). Using a MANOVA, results were calculated using age distance (as a continuous variable) as the independent variable, with the participant's total anxiety and depression scores as the dependent variables, measured as a group and independently. An A priori using G*Power was conducted to find a target population size using a MANOVA which produced a power of at least 0.95 and an effect size of at least 0.3 ($f^2=0.3, p = .05$), which yielded a total target sample size of 46 participants. Covariates included in this analysis includes sibship size (number of siblings) and number of siblings between the participant and their sibling with ASD which was run as a multivariate analysis of various with a covariate (a MANCOVA).

Research Question 4

Does biological sex affect the rates of generalized anxiety disorder symptoms and/or depression in neurotypical siblings of a person with ASD in a given sample? Participants were offered the option to select “prefer not to answer” when selecting biological sex, and any participants who selected this option were excluded from this analysis. Biological sex was the independent variable, with the participant’s total anxiety and depression scores as the dependent variable. Male and female were coded in SPSS as binary numbers (1 for male, 2 for female, and 3 for preferred not to answer). Statistics were gathered using a MANOVA of the independent variable and the dependent variables as a group and independently. An A priori using G*Power was conducted to find a target population size using a MANOVA to test the difference between two groups (male/female) which produced a power effect of least 0.80 ($p = 0.5$) and an effect size of 0.4. This yielded a target total sample size of 78 participants who select male or female as their sex.

Results

Descriptive Results

Correlations were run for demographic variables that were continuous variables (participants entered numbers that could be anything from 0 and more) against GAD-7 total scores. Positive correlations included age ($r = .13, p = < .00$), number of siblings raised with ($r = .22, p = < .00$), number of siblings between the respondent and their sibling with ASD ($r = .16, p = < .00$; Figure 1), number of biological siblings ($r = .28, p = < .00$; Figure 2) and being raised with foster siblings ($r = .17, p = < .00$; Figure 3). CES-D total scores and GAD-7 total scores were also positively correlated ($r = .36, p = < .00$).

Sibships varied significantly among the sample population. Overall, the number of siblings participants indicated that they were raised with varied from 0-24, with a mean of 5.18 and a standard deviation of 2.89, although 12 did not respond to sibship (N=488). Data pertaining to participant's responses to the number of siblings they were raised with can be found in Table 2.

Table 2*Siblings Raised With*

Sibling Type	Number Indicated	%
No Siblings	26	5.2
<i>Biological Siblings</i>		
1	377	75.4
2	64	12.8
3	28	5.6
4	4	0.8
5	5	1
<i>Adoptive Siblings</i>		
1	8	1.6
2	2	0.4
3	1	0.2
<i>Step-Siblings</i>		
1	81	16.2
2	82	16.4
3	88	17.6
<i>Foster Siblings*</i>		
1	78	15.6
2	73	14.6
3	83	16.6
5	1	0.2
<i>Extended Family Members*</i>		
1	83	16.6
2	110	22
3	84	16.8
4	11	2.2
5	22	4.4
6	7	1.4
7	4	0.8
8	3	0.6
9	2	0.4
12	3	0.6

14	1	0.2
20	1	0.2
22	1	0.2

*Only reported sibling numbers were included

Specifically in relation to their sibling with Autism, the majority of the participants identified as being older than their sibling with ASD (N=407), with 75 being younger than their sibling with ASD, and 17 being the same age as their sibling with ASD. 2 participants did not respond to the question pertaining to their or their sibling’s age. The overall age distances were between 13 years older and 33 years younger and a mean of 3.1 years older (SD = 4.01 years).

Figure 1

GAD-7 Scores by Number of Siblings Between Participant and their Sib with ASD

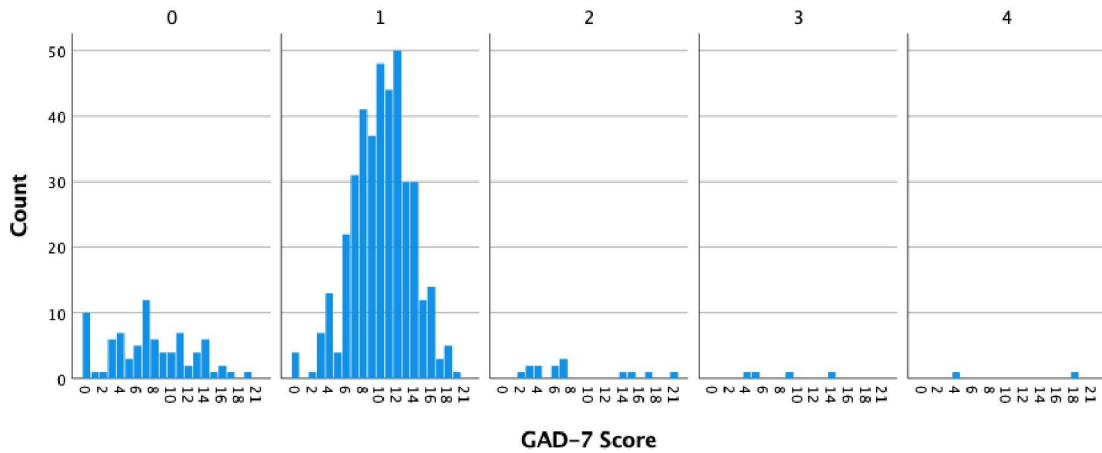


Figure 2

GAD-7 Scores by Number of Biological Siblings

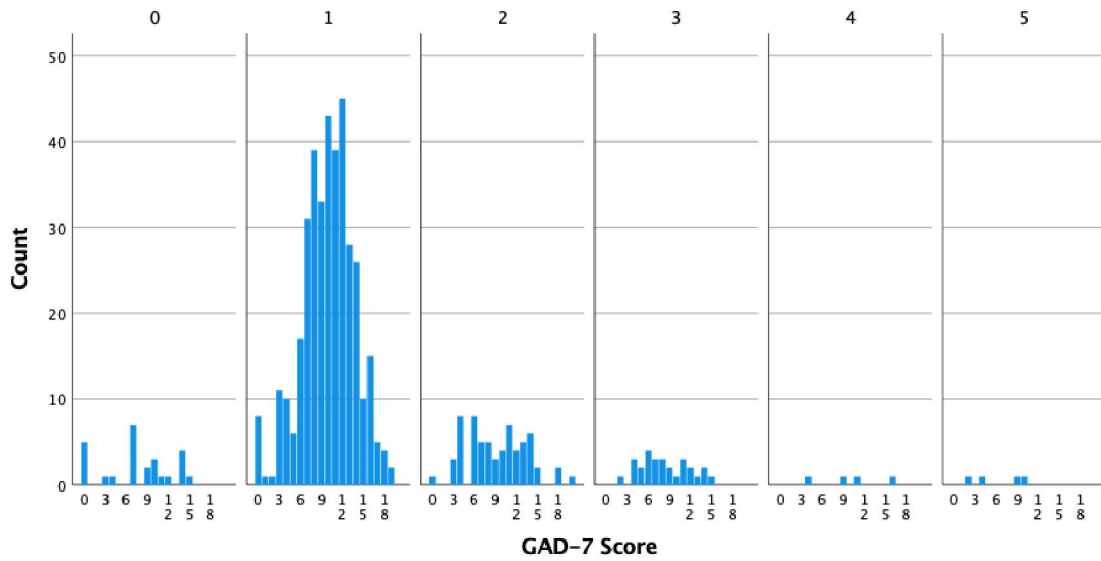
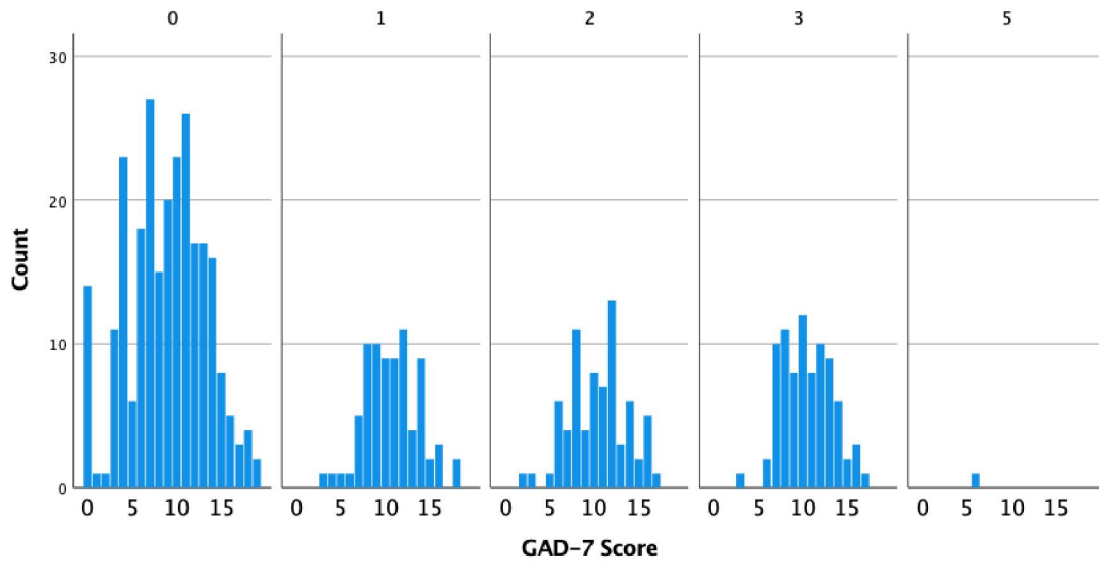


Figure 3

GAD-7 Scores by Number of Foster Siblings



CES-D scores were analyzed against other variables, additionally. Positively correlated variables which had significant correlations included age ($r = .20, p < .00$; figure 5), number of step siblings ($r = .25, p < .00$; Figure 4), number of foster siblings

($r = .28, p < .00$; figure 5) and number of siblings between the respondent and their sibling with ASD ($r = .13, p < .00$). Negative significant correlations included number of biological siblings ($r = -.19, p < .00$; figure 6) and number of extended family members raised with ($r = -.14, p < .00$).

Figure 4

CES-D Scores by Number of Step Siblings

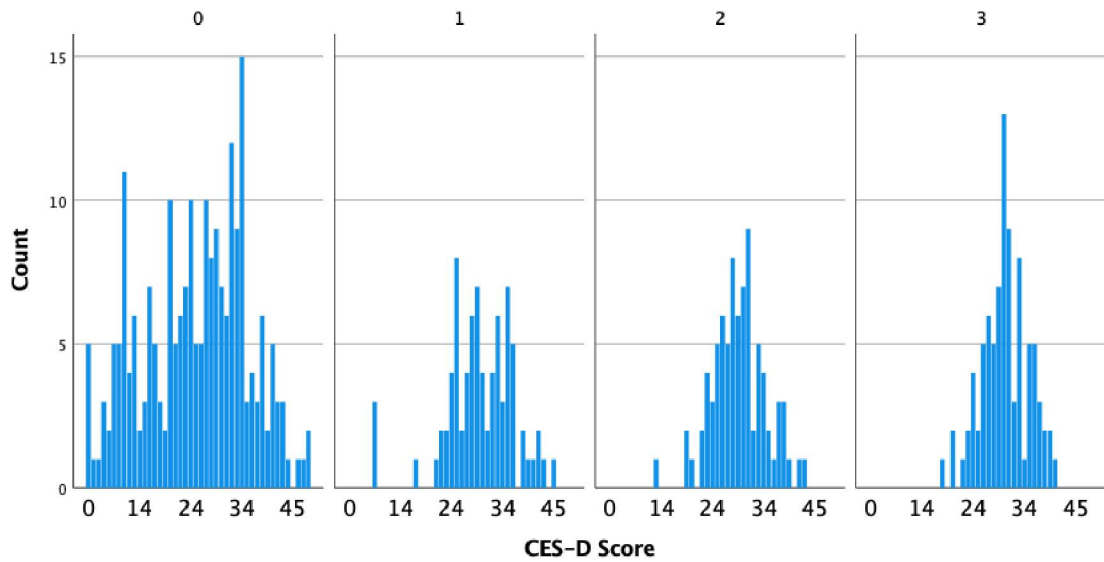


Figure 5

CES-D Scores by Number of Foster Siblings

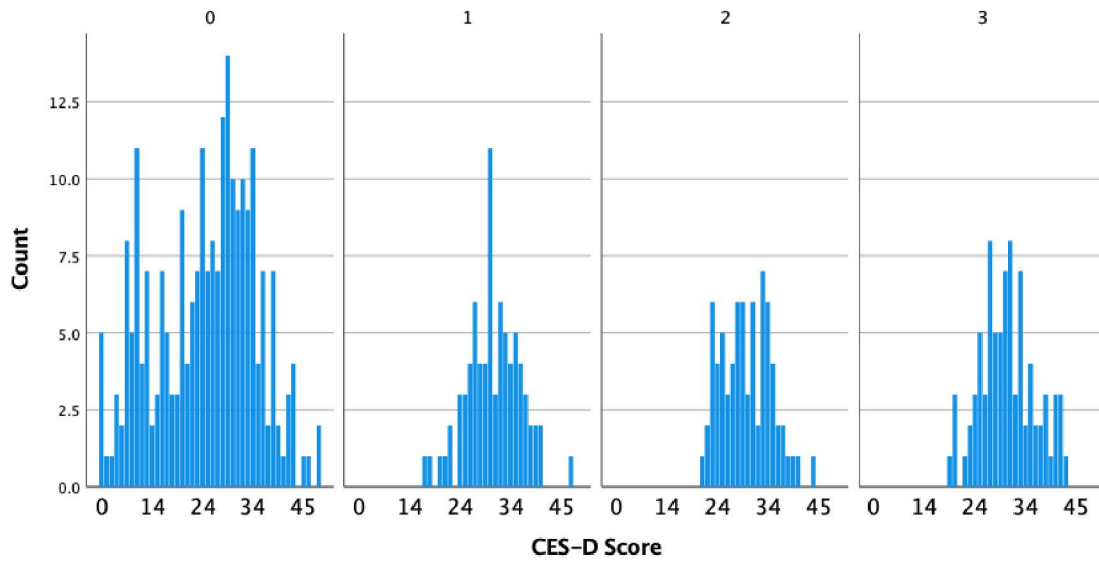
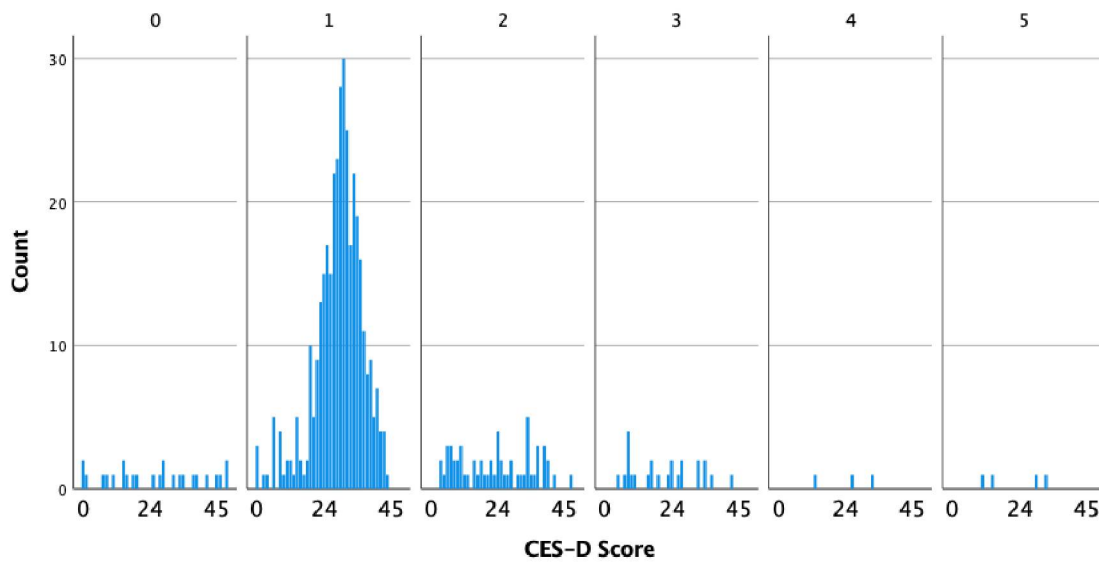


Figure 6

CES-D Scores by Number of Biological Siblings



Findings

Research Question 1: What is the prevalence of generalized anxiety disorder symptoms and/or depression in a sample of adult siblings of an individual with Autism Spectrum Disorder (ASD)?

Anxiety symptomology was analyzed according to Spitzer et al. (2006), using their guidelines to the GAD-7 in that scores of 5 should be considered mild anxiety, scores of 10 should be considered moderate anxiety, and scores of 15 and greater should be considered severe anxiety. Within the sample population, nearly half of the respondents (45.4%; $N = 227$) scored in the moderate anxiety range, with another large portion ($N=172$; 34.4%) of the sample scoring in the mild anxiety range as presented in Table 3. The mean score on was 9.67 ($SD = 3.89$), which is on the border between mild and moderate anxiety, according to the Spitzer et al (2006).

Depression scores were measured using the CES-D scale, utilizing the standard scoring set forth by Radloff (1977), in which total scores range from 0 to 60 and scores between 0 to 15 are to be considered *low depression*, scores between 16 to 20 *moderate depression* and scores of 21 to 60 are interpreted as *major depression is indicated*. The mean CES-D score in the sample population was 27.39 ($SD = 8.80$), which would be categorized as indication of major depression.

Within the present sample, the answer to the research question of “What is the prevalence of generalized anxiety disorder symptoms and/or depression in a sample of adult siblings of an individual with Autism Spectrum Disorder (ASD)?” is that participants were moderately anxious (45.4%) and had major depression (81.2%).

Similarly, 64.2% of all participants then reported clinically significant anxiety symptoms, and 85% reported clinically significant depression symptoms.

Table 3

GAD-7 and CES-D Scores by Descriptions

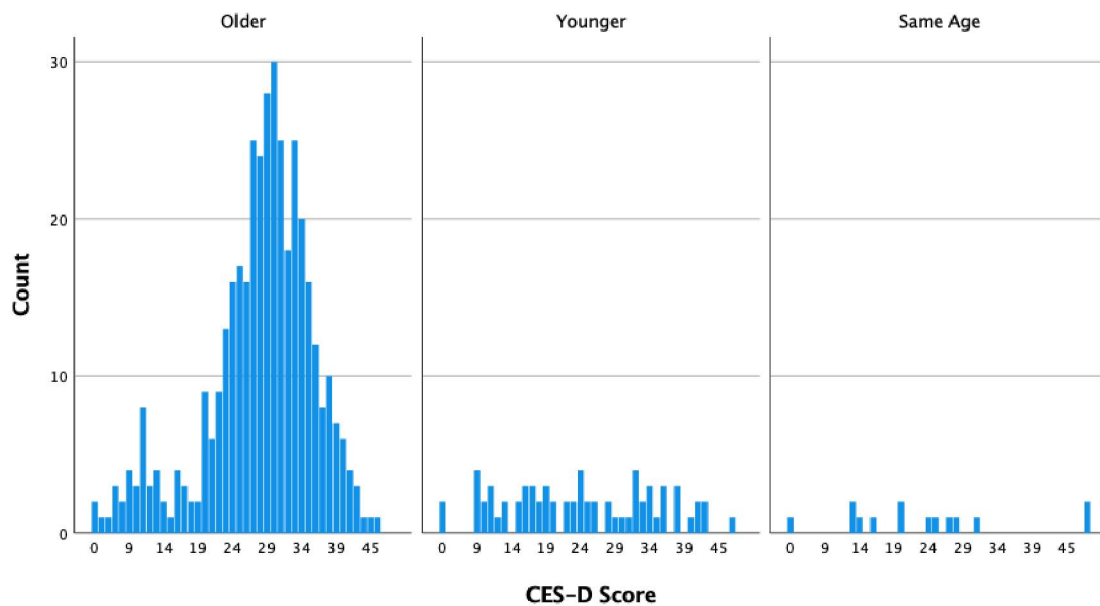
Description	Score Range	N	%
<i>Anxiety Symptomology (GAD-7)</i>			
No Anxiety	0-4	57	11.4
Mild Anxiety	5-9	172	34.4
Moderate Anxiety	10-14	227	45.4
Severe Anxiety	15+	44	8.8
Total		500	100
<i>Depression Symptomology (CES-D)</i>			
Low Depression	0-15	54	11.3
Mild-Moderate Depression	16-20	36	7.2
Major Depression is Indicated	21-60	389	81.2
Total		497	100

Research Question 2: Does being an older or younger sibling of the individual with ASD relate to the likelihood of generalized anxiety disorder symptoms and depression?

Within the sample population, the majority of respondents were older than their sibling with ASD (N = 395), with 68 being younger, and 14 were the same age. Those who indicated that they are the same age may either be twins with their sibling with ASD, or may be a foster sibling or step-sibling to a sibling with ASD, or themselves be a foster-sibling to a person with ASD. Table 4 depicts the descriptive data for these results (also see Figure 7).

Table 4*GAD-7 and CES-D Scores by Older and Younger*

Sibship	N	Mean	St. Deviation
<i>GAD-7</i>			
Same Age	14	9.57	5.55
Older	395	8.34	3.57
Younger	68	8.69	4.56
Total	477	9.73	3.85
<i>CES-D</i>			
Same Age	14	25.60	16.79
Older	398	24.47	7.81
Younger	68	26.75	11.03
Total	477	27.36	8.80

Figure 7*CES-D Scores by Older or Younger*

A multivariate analysis was conducted to test the effects of birther order on anxiety symptoms experiences by adult siblings. A MANOVA was run for birth order (older, younger or same age) and GAD-7 and CES-D total scores which resulted in a significant finding with a moderate effect size, $\Lambda = .73$, $F(50, 856) = 2.88$, $\rho < .01$. As

such, birth order does have a moderate effect on the anxiety and depression experienced by adult siblings, and the research hypothesis was rejected as younger siblings were not at higher risk of anxiety and/or depression within the given sample, and the null hypothesis supported.

Research Question 3: Does age distance from the individual of Autism affect the likelihood of generalized anxiety disorder symptoms and/or depression symptoms?

With the sample population, the age distances ranged from 13 years older to 33 years younger than their sibling with ASD, with a mean of 3.10 years older and a standard deviation of 4.09 years (Age Distance MSD = 4).

Siblings who were between 7 to 9 years younger than their sibling with ASD and siblings who were significantly older (12 and 25 years older) had the most acute CES-D scores within the sample population, as can be seen in Table 5. Similarly, those between 8 to 13 years younger than their siblings with ASD and those 25 years older had the most acute GAD-7 scores (see Figure 8). A MANOVA analyses run in SPSS showed that, within the given population, age distance had a significant but mild effect on anxiety of $\Lambda = .95$, $F(50, 946) = .565$, $p < .01$. As such, while older siblings as a group had overall higher GAD-7 and CES-D scores, there were distinct in-group differences with age distance that show variances in these effects. It should be noted that both the overall model and independent models were significant and had moderate effect sizes.

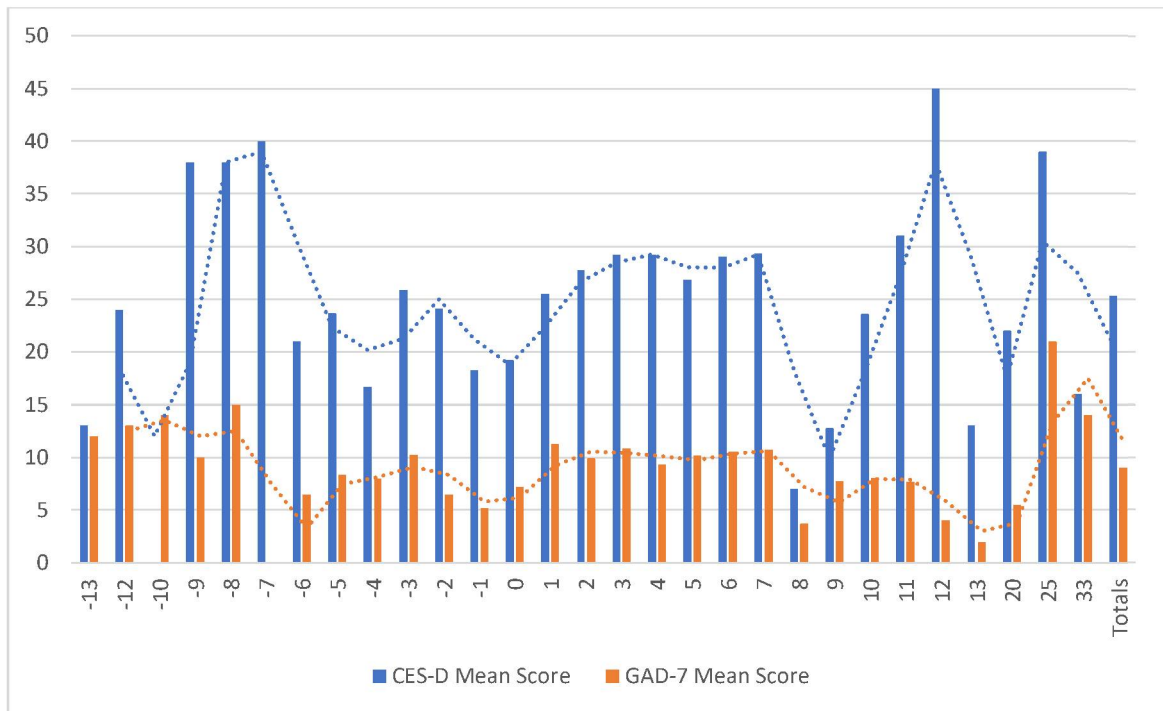
Table 5*Distribution of Age Distance & GAD-7 & CES-D Score Means*

Age Distance	N	GAD-7		N	CES-D	
		Score Range	Mean Score		Score Range	Mean score
-13	1	0	12	1	0	13.00
-12	1	0	13	1	0	24.00
-10	1	0	14	0	-	-
-9	1	0	10	1	0	38.00
-8	1	0	15	1	0	38.00
-7	1	0	0	1	0	40.00
-6	9	1 - 13	6.5	9	9 - 49	21.00
-5	10	3 - 16	8.33	9	9 - 41	23.67
-4	3	4 - 14	8	3	11 - 22	16.67
-3	18	4 - 19	10.22	17	9 - 42	25.88
-2	21	0 - 13	6.48	18	0 - 42	24.11
-1	8	0 - 14	5.13	7	10 - 28	18.29
0	16	0 - 17	7.19	14	0 - 31	19.25
1	24	4 - 18	11.25	24	11 - 37	25.52
2	49	0 - 17	9.90	48	0 - 42	27.77
3	79	0 - 19	10.87	77	0 - 42	29.26
4	94	2 - 16	9.31	92	7 - 43	29.26
5	67	0 - 18	10.16	67	6 - 39	26.84
6	44	3 - 18	10.55	44	9 - 41	29.09
7	25	4 - 17	10.72	23	12 - 41	29.39
8	3	0 - 7	3.67	3	4 - 9	7.00
9	4	5 - 11	7.75	4	7 - 26	12.75
10	10	4 - 18	8.1	5	20 - 27	23.60
11	3	6 - 10	7.67	3	27 - 37	31.00
12	1	0	4	1	0	45.00
13	1	0	2	1	0	13.00
20	2	4 - 7	5.5	2	16 - 28	22.00
25	1	0	21	1	0	39.00
33	1	0	14	1	0	16.00
Totals	500	0 - 18	9.04	478	0 - 49	25.30

NOTE: Only age distances that were reported by participants were included

Figure 8

Distribution of Age Distance and GAD-7 & CES-D Scores



Research Question 4: Does biological sex affect the rates of generalized anxiety disorder symptoms and/or depression in adult siblings of a person with ASD in a given sample?

The mean scores for both the GAD-7 and CES-D between male participants, female participants and those who chose not to answer for their biological sex (listed herein as “Other”) were close to the overall mean scores and did not differ significantly with $\Lambda = .99, F(4, 856) = 1.33, p = .26$. In all three biological sex categories, nearly half of participants fell in the “moderate anxiety” category, with the next largest category being “mild anxiety” (See Table 12). Depression scores as measured by the CES-D were also very similar between biological sexes and the total sample means as shown in Table 6.

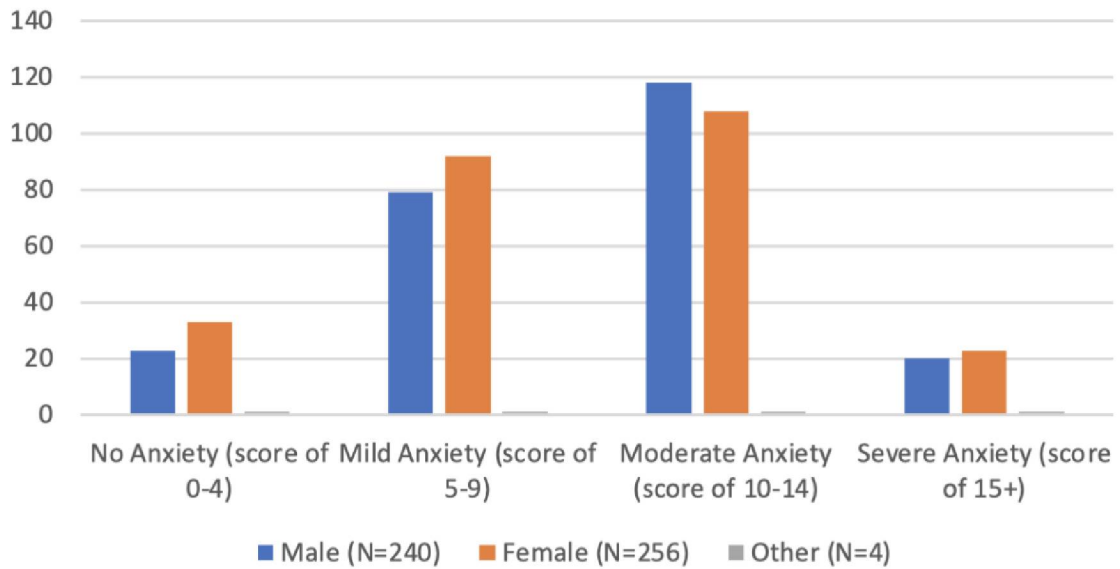
While the overall model was not significant and did not show an effect size for sex on anxiety and depression, scores, independently run analyses showed that there were some effects. Specifically, anxiety was not affected by biological sex: $\eta_p^2 = .98$, $F(2, 429) = .3$, $p = .98$, whereas depression was statistically affected by sex: $\eta_p^2 = .02$, $F(2, 429) = 4.23$, $p = .01$. Given these results, the research hypothesis was partially supported.

Table 6*GAD-7 Scores by Sex*

	N	Range	Mean	Median	St. Dev.
Male	240	0-19	8.62	8.00	4.17
Female	256	0-21	8.62	8.50	4.42
Other	4	3-15	9.75	14.50	0.71
Total	500	0-21	9.67	10.00	3.89

Table 7*GAD-7 Scores by GAD-7 Descriptions*

	No Anxiety (score of 0-4)		Mild Anxiety (score of 5-9)		Moderate Anxiety (score of 10-14)		Severe Anxiety (score of 15+)	
	N	%	N	%	N	%	N	%
Male (N=240)	23	0.96	79	32.92	118	49.17	20	8.33
Female (N=256)	33	12.89	92	35.94	108	42.19	23	8.98
Other (N=4)	1	25	1	25	1	25	1	25
Total (N=500)	57	11.4	172	34.4	227	45.4	44	8.8

Figure 9*Distribution of GAD-7 Scores by Level and Sex***Table 8***CES-D Scores*

	N	Range	Mean	St. Dev.
Total	479	0 – 60	27.39	8.80
Male	231	0 – 60	27.38	9.70
Female	244	0 – 60	27.29	10.66
Other	4	11 - 33	30.00	4.24

Figure 10

CES-D Scores by Sex

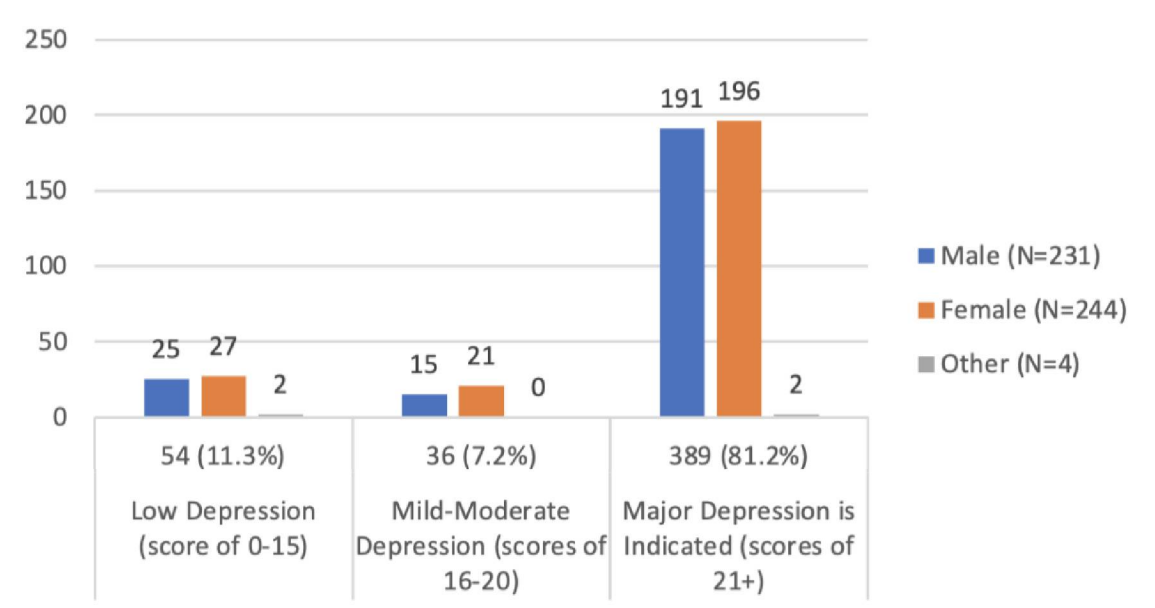


Table 9

CES-D Scores by CES-D Description

	Low Depression (score of 0-15)		Mild-Moderate Depression (scores of 16-20)		Major Depression is Indicated (scores of 21+)	
	N	%	N	%	N	%
Male (N=231)	25	10.82	15	6.49	191	8.27
Female (N=244)	27	11.07	21	8.61	196	80.33
Other (N=4)	2	50.00	0	0	2	50.00
Total (N=479)	54	11.3	36	7.2	389	81.2

Summary

The results found multiple correlations which were not part of the original research questions. Age had a significant effects on depression scores, while being raised with either foster or biological siblings also had a significant impact on depression.

However, these findings did not seem to have effects on anxiety scores.

Within the research questions, the over 45% of the sample population was clinically anxious, and over 81% scores in the range of being clinically depressed. Whether someone is an older or younger sibling than their sibling with ASD also has a significant impact on the likelihood of experiencing anxiety or depression, with older siblings being more likely to experience both. However, within each group (older and younger siblings), there were variations that affected the experience of anxiety and depression symptoms measured. Those who were younger siblings as a group had lower anxiety and depression scores than older siblings, but the most acute cases of GAD-7 and CES-D scores were seen between age distances of 8 and 13 years younger than the sibling with ASD. Similarly, those who were 25 years and older than their sibling with ASD showed significantly acute GAD-7 and CES-D scores. Lastly, biological sex appears to have a significant impact on a siblings' likelihood of experiencing depressive symptoms with females being at a higher risk, but not anxiety.

Chapter 4

Discussion

The present study sought to explore the prevalence of anxiety and depression symptomology in adult siblings of individuals with Autism, as well as whether factors such as sibship, age distance and sex have an effect on the presence of symptomology. Within the studied sample of self-reported adult siblings, there was a significant portion that showed both anxiety and depression symptoms. Sibship did seem to have an impact on the presence of symptomology, with older siblings as a group having more elevated symptomology, which contradicted the study's hypothesis that younger siblings would show higher rates of anxiety and depression than older siblings. However, when analyzing for age distance, it was found that there were within group (older and younger) differences. Biological females in the sample showed higher rates of depression symptoms, but not anxiety, which partially confirmed the study's hypothesis that females would have both higher rates of depression and anxiety.

Prevalence of GAD and Depression Symptoms

In response to the first research question regarding the prevalence of GAD and depressive symptoms with a sample of Autism sibs, the study showed that there was a high rate of anxious and depressive symptoms in the studied sample. Over 34% of the sample measured as having severe GAD symptoms, with the majority of participants (45.4%) measuring with moderate anxiety symptoms. Depressive symptoms were also very high within the current sample. The large majority (81.2%) of respondents reported major depressive symptoms, with 88.7% of the total sample reporting clinically significant depressive symptoms. For reference, the U.S. Center for Disease Control

(CDC) estimated that 15.6% of US adults qualify for a diagnosis of generalized anxiety disorder in 2019 (Terlizzi et al., 2020), and 7.8% of US adults qualifying for a diagnosis of major depressive disorder (NIMH, 2019). While the methodologies used in the CDC survey were different than the present study, this point of reference shows that the sample of siblings in the present study exhibited generalized anxiety symptoms and depressive symptoms at comparatively high rates. It should again be noted that these findings should not be generalized to the greater population of people with siblings with ASD as the sample population is not truly representative of the general population.

Sibship and GAD and Depression Symptoms

The second research question explored whether sibship (being an older or younger sibling as their sibling with autism) is associated with anxiety or depressive symptoms. The present study hypothesized that younger neurotypical siblings would exhibit higher rates and degrees of anxiety and depressive symptoms. Within the sample population, the majority were older siblings (79%), and a small portion reported to be the same age as their sibling, which may mean that they were presumably either twins or adoptive/step siblings of the same age (2.8%), although the present study did not inquire twin or adoptive status. The effect of sibship was small but statistically significant between older and younger sibling's anxiety levels, with older siblings having an average score of 10 and younger having an average score of 8, and those of the same age having an average score just under 9. The results were similar for depression symptoms, with older siblings having the highest average CES-D scores of 28, 24 for younger siblings and 25 for same age siblings. Sibship effects were larger for anxiety than it was for depression among siblings. It should be noted that despite these differences, all groups'

averages were still in a clinically significant range of anxious and depressive symptoms. In summary, while all sibships exhibited clinically significant anxious and depressive symptoms, older siblings as a group did so to a higher degree than siblings who were younger or the same age as their sibling with Autism. Given these findings, the research hypothesis was rejected for the present study with the participant population, and the alternative hypothesis was accepted. These findings counter that of previous literature, such as Montes (2018), which found that older siblings showed less anxiety symptoms than younger siblings. It could be postulated that adult siblings may have higher rates of depression than youth or child siblings, as was the population in Montes (2018).

Age Distance and GAD and Depression Symptoms

The third research question asked whether the age distance that a neurotypical sibling has from their sibling with autism effects the presence of anxiety and/or depressive symptoms. As the literature is severely lacking in any current evidence as to age distance effects, no hypothesis was offered for this research question and was thus exploratory in nature.

Within the present study population, age distance had a statistically significant mild effect on both anxiety and depression symptoms. Specifically, participants who were 4 years younger than their sibling with ASD had the most elevated anxiety symptoms, and those 5 years younger had the most elevated depressive symptoms. These findings clarify the findings from research question 2 of whether being an older, younger or same-aged siblings has an effect. While older siblings have, on average, higher anxiety and depressive symptoms, the groupings of older and younger siblings hid some specific subgroup results from age distance. Anxiety scores as measured by GAD-7 scores were

the most acute in siblings 7-9 years younger and in siblings 12 and 25 years older than their sibling with ASD. Depression scores as measured by the CES-D were likewise the most elevated in siblings 8-13 years younger, and 25 years older and up. However, when controlling for number of siblings between the participant and their sibling with ASD, the effects of age distance on anxiety and depression decreased. As such, it may be the case that having siblings between the neurotypical sibling and the sibling with ASD was a protective factor and should be explored in future research.

Biological Sex and GAD and Depression Symptoms

Whether biological sex has any effect on a neurotypical sibling of a person with ASD experiencing anxiety and/or depressive symptoms was the basis of the fourth and final research question. Given that females tend to be at a higher risk of internalizing behaviors within the U.S. and that female siblings of a person with ASD tend to engage in more parentification, the hypothesis stated females would be at a higher risk of experience both anxiety and depression symptoms. The participant population was well diversified between the sexes, which lead to a sufficient sample in which to test this research question (256 females, 240 males and 4 identifying as “other”). Although the anxiety and depression symptoms were high among all the participants, female participants showed higher rates of depression, while no differences were seen in anxiety. With these results, the research hypothesis partially confirmed. This also confirms previous studies, such as by Esfahani et al. (2018), which found that females tend to show internalizing behaviors at higher rates than males. These findings may indicate special circumstances for male neurotypical siblings that are not experienced by the general population, such as higher resiliency as was shown by Corsano et al. (2017) and warrants

further exploration. It should be noted that given the small sample size of individuals who chose not to identify as either biologically male or female, no statistical conclusions could be drawn. It may be that these are non-binary or gender-fluid individuals or may not have wanted to disclose their biological sex. Exploring the effects of gender identification with adult siblings also warrants additional research.

Additional Findings

Correlations analyses were run across demographics and the research variables for total measured depression and anxiety symptoms. Within these evaluations, several statistically significant correlations were identified outside of the scope of the present study's focus. One significant correlation was age and anxiety symptoms. That is, increased age was associated with higher anxiety symptom scores. This is in line with the research, as older neurotypical siblings tend to take on more responsibilities for their sibling with Autism and in preparing for their parent's end-life plans and future care for their sibling with Autism (Moss et al., 2019).

Number of siblings between the participant and the sibling with ASD and anxiety were associated. Additionally, the participants' number of biological siblings was positively correlated with higher reported anxiety symptoms. That is, when a participant was raised with more siblings, their anxiety levels tended to increase. It should be noted that within the present study, this included not only biological siblings, but foster siblings, stepsiblings, cousins and more. As such, more research is needed to parse out the different types of familial relationships and their impact on anxiety with neurotypical siblings of someone with autism.

In addition to the number of siblings one was raised with having an effect on anxiety symptoms, those who reported being raised with foster siblings also had a significant positive correlation with anxiety symptoms. Those who reported having been raised with at least one foster sibling generally reported higher levels of anxiety than those who reported other types of sibling relationships. The current literature seems to support this finding that levels of stress and anxiety are higher among children who have adoptive or foster children placed in their home (Hunsley, Ekas & Crawley, 2021).

Lastly, as was expected from the current literature, there was a significant positive correlation between reports of anxiety symptoms and reports of depressive symptoms. That is, those who reported higher levels of anxiety also reported higher levels of depression. This is supported in the literature which states that internalizing behaviors tend to lead to a mixture of anxious and depressive symptomology (Gorman, 1996; Moffitt et al., 2007; Orsmond & Seltzer, 2009; Salcedo, 2018).

Practical and Clinical Implications

The present study highlighted several aspects of mental health functionality that siblings of someone with Autism experience which have important clinical implications. Although previous research has not delved into anxiety and depression prevalence among adult siblings, the present study certainly confirms research which has explored the significant experience of internalizing behaviors in adult siblings (e.g. Tomeny, Ellis et al., 2017; Nimmo-Smith et al., 2020). While Nimmo-Smith et al (2020) found that siblings were 250% more likely to qualify for an internalizing disorder, the present study showed this rate to be closer to 511% for anxiety symptoms and depression symptoms being 1,137% more likely than in the general population (Terlizzi et al., 2020; NIHM,

2019). This study validates the need for anxiety and depression supports and public education for adult siblings to be addressed. Given the large disparity in figures, additional research with larger population sizes is certainly warranted to evaluate the true national prevalence rates of internalizing behaviors. In the meantime, it can be inferred that adult siblings of someone with Autism are more likely to engage in these internalizing behaviors and are thus more likely to experience anxiety and depression symptoms than the general population. As such, clinicians, educators and public health officials should continue to implement and evaluate supports for adult siblings and their families.

Internalizing behaviors, often exhibited through anxiety and/or depression, are common amongst siblings of a person with ASD (Esfahani et al., 2018). However, little research has shown what effect birth-order has on the degree of internalizing symptoms. As the present study showed that older siblings were at a higher risk of anxiety and depression symptoms, clinicians and educators can provide families with additional psychoeducation for their family unit when serving an individual with Autism. Similarly, as the present study showed that siblings 8 and more years younger and those significantly older than their sibling with Autism were most likely to experience more internalizing behaviors, clinicians and public health figures can identify children and siblings in that age distance range to provide additional familial support. Although siblings in that range were found to be more acutely anxious and depressed, older siblings were also found to in general have higher rates of anxiety and depression.

Lastly, the experiences of family and sibship dynamics needs to be explored further. As the present study found strong correlations between anxiety and number of

siblings and was specifically high when a sibling was a step-sibling, more qualitative information is needed to determine contributing factors to these findings. That is, more research is needed to examine whether having these familial relationship does indeed raise the risk of experience anxiety and depression symptoms, or whether there are other factors that were not accounted for in the present study. A limitation of the present study is that it did not ask whether the participant was the foster child in the family, or whether they were a biological child who also had a foster sibling. Likewise, the present study did not investigate whether the sibling with ASD was a foster-sibling or biological sibling. Given these gaps in the study, additional research is warranted into the effects of both being a foster sibling, and having a foster sibling with ASD.

In general, the present study shows a strong need for support for siblings within the Autism community. Although supports for the individual with Autism and their parents have been growing tremendously over the last several decades, the present study may show the lack of support present for siblings as may be seen in their high anxiety and depression scores. When providing diagnoses for Autism, clinicians can also provide additional information on the impacts that this diagnosis may have on the family unit, specifically with NT siblings. Public health and education officials can also work to improve community awareness of these experiences, and schools can help identify siblings for additional supports.

The presence of high rates of anxiety and depression among siblings provides a foundation for clinical applications. First, online and in-person groups can be formed to provide a space for siblings to share and normalize their experiences. Some such groups are already emerging, such as can be found on Facebook (Support Group for Siblings of

Autism and Special Needs, 2017). However, the best route of support would be to provide education and support to parents and families as early in life as possible to help prevent symptomology. For example, when clinicians diagnose a child with Autism, they have the opportunity to education the family on not only the implications for the diagnosed individual, but for the parents and any siblings and other family members present in the household or for future children. Clinicians can then provide resources to parents on how to best support not their diagnosed child and themselves, but the siblings as well, or help point them to where to find resources. Schools can also be a major source of support for siblings. As children spend a large portion of their developing years in the education system, teachers and counselors can be educated on signs of anxiety and depression symptoms to watch for in known siblings, and to help provide social and emotional support for these children. Most importantly, parents, educators, clinicians and other supports can be empowered with the knowledge that these siblings are likely silent sufferers of anxiety and depression symptoms to validate and normalize the sibling's experiences, thoughts and feelings.

Study Limitations

While the present study had important findings, there were limitations present in the design and analysis. Number of siblings with ASD, the psychological impacts of COVID-19, sibling relationships and ASD sibling functioning were not accounted for in the present study among other considerations. Specifically, as research has shown that siblings with ASD that have more acute behavioral needs, lower cognitive functioning, or both, have significant negative impacts on siblings (eg. Tomeny, Ellis et al., 2017;

Hastings & Petalas, 2014). These were not accounted for in the present study, and requires further exploration.

Of note, the sample population was well divided between males and females, which is fairly representative of the population at large. In the studied sample, 51.2% were female with 48% male, as compared to the U.S. average of 50.9% female and 49% male (US Census Bureau, 2019). The average age of the sample population ($M = 33$) was slightly younger than that of the U.S. ($M = 38.3$) (US Census Bureau, 2019). Similarly, the U.S. racial demographics include 76.3% White, 13.4% Black, 1.3% American Indian, 18.5% Hispanic and 5.9% Asian (US Census Bureau, 2021), as compared to the studied sample of 93.2% White, 2% Hispanic, 1% Black and less than 1% for all other ethnicities. Therefore, the data gathered and results may be somewhat representative of the U.S. population at large in terms of biological sex representation but falls short of being truly representative due to ethnic disparities within the studied sample as compared to that of the U.S. total population.

The questionnaire presented for the present study asked solely for number of siblings and whether participants had “a” sibling with ASD. However, it did not account for those who may have more than one sibling with ASD, or those who had a sibling with ASD as well as siblings with other physical, intellectual or other developmental disabilities. As according to Sandin, et al. (2014) the likelihood of having another child with autism increases by 10-fold once a child with ASD is present in the family, there is a high likelihood that participants in the present study had more than 1 sibling with ASD, which was not accounted for. Similarly, this could affect the sibship results, as participants may have both older and younger siblings with ASD, which would in turn

affect their age distances. Some participants, then, may have had to choose which sibling to report on if this was the case which may have confounded the results. Moreover, the present study did not account for participants who either are presently or have in the past been secondary or primary caregivers of their sibling with ASD, or are current legal guardians of their sibling, which could potentially have a significant impact on levels of stress and responsibility experienced by the participant.

The present study did not inquire whether participants had been previously diagnosed with any mental health conditions. Therefore, they were not referred to in this study as neurotypical, as this was not confirmed. Similarly, as whether or not someone had already been diagnosed with anxiety or depression was investigated, some participants may have been more aware of their symptomology than others, and some may have already been receiving support or treatment for their symptoms while others may not have. Hence, it is unknown how these factors may have impacted the results.

When examining the findings related to age distance affects for anxiety and depression symptomology, one limitation within the sample is the distribution of age distances. Within the present sample, although the full range of age distances were from 13 years younger to 33 years older, the majority of participants were between 6 years younger and 10 years older than their sibling. Most age distances outside of -6 and +10 only had 1 participant within that age distance. As findings in the present study were that the most acute depression and anxiety scores were in participants 8+ younger and 25+ older, the sample sizes of these age distance groups leads to questions of validity and reliability of the present findings. Research specifically into age distances that have

stronger sample sizes for the different age distances is necessary to better understand the potential effects that age distance has from siblings with ASD on NT siblings.

Another limitation is the potential confounding variable of the effects that the COVID-19 pandemic may have had on participants functioning. Data collection took place in 2021, during the same time that the COVID-19 pandemic restrictions were in effect in the United States at varying degrees in each State (CDC, 2012). Studies have shown that the widespread prevalence of anxiety and depression increased during this time due to the social isolation that resulted from the quarantine and public lockdowns (Zhu et al., 2021). Effects of the quarantine were not accounted for in the present study, and consequently, results herein relating to prevalence and intensity of anxiety and depression symptoms may be impacted by the COVID-19 pandemic.

While the present study found high rates of anxiety and depression in NT siblings, the present study was not an experimental study (that is, it did not have a control group and experimental group), nor was it an epidemiological study. As such, there are many inferences that cannot be made about the prevalence rates found in the current study. However, given the high rate of internalizing behaviors shown in both the present study and previous research, further research utilizing mixed-methods, using both quantitative and qualitative data may be warranted to better understand the experiences of and support siblings.

The present study did not take covariates that may contribute to anxiety and/or depression into account. Such factors may have been diet, geographical location, social supports, sleep habits, exercise, family history, current mental health diagnoses, therapeutic supports for the sibling with ASD, ASD functionality and severity and more.

While the present study found several significant effects and correlations, specific contributing factors for depression and anxiety are unable to be drawn to solidify conclusions of how the variables relate to each other. Additionally, while the questionnaire asked about current household income, it did not inquire into the household income or overall socioeconomic status of the participant's home growing up. This factor may have significantly impacted their experiences in childhood with long-term consequences, which was not evaluated within the present study and similarly warrants future research.

Relationship quality and relationship types that participants have had and had at the time of their participation was not measured. As previous literature has shown a strong link between siblings who engage in sibling- and parent-focused parentification and sibling internalizing behaviors (Tomeny et al., 2017), the present study was unable to account for such effects. Additionally, the function level of the sibling with ASD was not measured. As challenging behaviors and level of functioning in the sibling with autism may have an impact on neurotypical siblings (Garrido, Garballo & Garcia-Retamero, 2020; Braconnier et al., 2018), the present study was unable to identify whether these factors impacted the findings herein.

Lastly, the type of supports and level of support that participants had growing up and at the time of participation in the present study was not analyzed. Research has shown that sibling relationship with their parents and whether they feel supported by their parents has a major impact on mental health, which was not accounted for in the present study (Schuntermann, 2007). Similarly, early social supports for siblings relating to their

experiences being a sibling of someone with Autism was also not evaluated, and may impact the sibling's mental health, although the literature has not yet examined this.

Future Directions and Recommendations

The limitations present in the current study also offer future research directions to better understand the experiences of siblings. For example, as the present study did not differentiate between siblings who had one or more than one sibling with ASD, future researchers may examine the effects that having more than one sibling with ASD may have on an individual.

Conducting the present study with a stratified population to match the national racial and ethnic makeup would also be beneficial to be able to better generalize the findings. While the present study had a healthy population size and a fairly representative biological sex representation, it was an overly White population and did not represent minority populations well.

While the present study found that older siblings were more likely to experience anxiety and depression as a whole, within group differences with age distance may have a significant impact on the experienced symptoms of anxiety and/or depression. As a result, research is needed into why this phenomenon was noted, and whether this result was limited to this sample or is a general experience among siblings. As the present study examined variables from a purely quantitative standpoint, qualitative data could additionally be beneficial in understanding the correlations between anxiety, depression and sibling experiences and contributing factors therein. Additional research on how factors such as diet, sleep, adult relationships (spouses, children, etc.), exercise, perceived parental support, social supports, religiosity and more affect the outcomes of siblings'

mental health would help bolster the current understanding of their functioning as well as help point out psychoeducation and support opportunities. Furthermore, as sibling relationship quality was not studied, additional research into whether quality of and ASD sibling relationships affect anxiety and depressive symptoms is warranted.

Lastly, as the present study collected its data and was conducted during the 2020-2021 COVID-19 pandemic, a replication of the present study during at time of typical community health (eg. When there is not a global or local pandemic occurring at the time of data collection) is warranted. As was noted by the CDC (2012) and Zhu et al. (2021), the COVID-19 pandemic led to increased feelings of isolation and significant increases in anxiety and depression overall in the U.S. As such, a replication of the current study if and when these effects have been reduced to their baseline state would help bolster the current clinical knowledge.

The implications of the results shown by this study do not only call for additional research opportunities to better understand the sibling population, but also for additional community and individual support for siblings. Mental health clinicians, educators, physicians, first responders and all those in the helping field would benefit from understanding the ramifications and implications that being an sibling of someone with ASD may have. This information may be specifically advantageous for clinicians who diagnose ASD, as they can then assess the family dynamics and provide helpful information to parents and other supporters for the potentiality of anxiety and depression in siblings. Families can then seek out preventative supports and better education in how to help their children in maintaining robust familial mental health. Mental health

clinicians can also use this information with patients and clients with siblings with ASD to help assess for anxiety and depression and normalize their experiences.

Conclusions

Throughout the last several decades, the literature has been exploring the effects that having a child or adult with ASD has on the family unit. While this research has largely focused on the parental experiences, investigations into the experiences of neurotypical siblings has been increasing. The present study sought to answer research questions regarding the prevalence of anxiety and depression symptoms in neurotypical siblings and whether factors like age, biological sex, birth order and age distance bear any effect on these symptoms. There were 500 participants in total which were well split in terms of biological sex and were mostly an older sibling sample with an average age of 33. The present study found that nearly 80% of participants showed anxiety symptoms at a clinical level and over 81% experiencing major depressive symptoms with biological sex not having a statistical effect on these outcomes. Within the studied population, older siblings tended to experience more anxiety and depression than same-aged or younger siblings, although siblings 4-5 years younger than their sibling with ASD experienced the most acute anxiety and depressive symptoms. Other factors such as age and number of biological siblings also were found to have effects on the presence of anxiety and depressive symptoms. Further research is needed to examine the limitations of the present study, as well as to further understanding of the sibling experience. Lastly, clinicians, educators and public health officials will benefit from this information and future research in supporting the holistic health of families affected by ASD. As siblings are a core part of the family unit, their wellbeing is of equal importance to that of their parents

and sibling with ASD and of the family as a whole, and the literature and supports available to them should reflect such.

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Appendix A

Consent Form

Welcome to this study. The study is being conducted by Matthew Arnold of Northwest University to meet the requirements of his doctorate dissertation. The study has been approved by the Northwest University Institutional Review Board. No deception is involved, and the study involves no more than minimal risk to participants (i.e., the level of risk encountered in daily life). The risks encountered may cause uncomfortable feelings such as emotional distress due to answering questions of a personal nature. If any questions or content of this questionnaire bring up personal questions, confusion, or anxiety, you may seek help by contacting the Crisis Text Hotline by texting 741741. In addition, Psychology Today at www.psychologytoday.com is a resource to find a referral for a counselor in your area.

Participation in the study is expected to take 5-10 minutes and is strictly anonymous. You begin by answering a series of demographic questions, followed by questions regarding your experiences over the last two weeks. Your responses will be treated confidentially and will not be linked to any identifying information about you. You may discontinue the questionnaire at any time if you wish. The results from this study will be presented within research papers and may be shared at a professional conference or presented in academic settings. All data forms will be destroyed on or before December 31, 2024. Electronic data with no identifying information will be kept indefinitely.

You will have the opportunity to enter to win 1 of 4 \$25 Amazon gift cards in a raffle. Participation in the raffle requires completion of the entire survey, as well as a valid email address. If you chose to participate in the raffle, your email will be stored separately from the questionnaire as to not identify your email with your responses. Only 1 entry per participant. Winning in the raffle is not guaranteed. Winners will be notified within 30 days of the closing of the survey and notified via email. Gift cards will be distributed digitally via the email provided.

If you have further questions about this study or their rights, or if you wish to lodge a complaint or concern, you may contact the principal investigator, Matthew Arnold, Email: matthew.arnold13@northwestu.edu; Dr. Leihua Edstrom, Northwest University College of Social and Behavioral Sciences, at (425) 889-5367, Email: leihua.edstrom@northwestu.edu; or the Chair of the Northwest University Institutional Review Board, Dr. Cheri Seese, at cherri.seese@northwestu.edu or (425) 285-2413.

Before taking part in this study, please read the consent form below and click on the "I Agree" button at the bottom of the page if you understand the statements and freely consent to participate in the study. You may exit the survey at any time.

Thank you for considering participation in this study.

Matthew Arnold

Doctoral Student in Counseling Psychology
College of Social & Behavioral Sciences
matthew.arnold13@northwestu.edu

Leihua Edstrom, PhD, ABSNP
Professor of Psychology
College of Social & Behavioral Sciences
leihua.edstrom@northwestu.edu

Please print a copy of this consent form for future reference

If you are 18 years of age or older, understand the statements above, and freely consent to participate in the study, click on the “I Agree” button to begin the survey

- I Agree
- I Disagree and Wish to Exit

Appendix B

Qualtrics Survey

What is the year you were born? Please enter in numeric form (example: "1985").

Do you have a sibling who has been professionally diagnosed with Autism Spectrum Disorder (ASD)?

- Yes
- No

What is the year of birth for your sibling with Autism (ASD). Please enter in numeric form (example: "1985").

What is your sex?

- Male
- Female
- Prefer not to answer

Choose one or more races/ethnicity that you consider yourself to be:

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Latina/o
- Other _____

What is the highest level of school you have completed or the highest degree you have received?

- Less than high school diploma
- High school graduate (high school diploma or equivalent including GED)
- Some college but no degree
- Associate degree in college (2-year)
- Bachelor's degree in college (4-year)
- Master's degree
- Doctoral degree
- Professional degree (JD, MD)

Information about income is very important to understand. Would you please give your best guess? Please indicate the answer that includes your entire household income in (previous year) before taxes.

- Less than \$10,000
- \$10,000 to \$29,999
- \$30,000 to \$59,999
- \$60,000 to \$89,999
- \$90,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 or more

What State do you live in? (If outside the US, please specify)

Are you now married, widowed, divorced, separated or never married?

- Married
- Widowed
- Divorced
- Separated
- Never Married

Please indicate your occupation:

- Management, professional, and related
- Service
- Sales and office
- Farming, fishing, and forestry
- Construction, extraction, and maintenance
- Production, transportation, and material moving
- Government
- Retired
- Unemployed
- Full-time student

Please enter the number of siblings you were raised with (biological or adopted) as it pertains to you.

- Biological Siblings _____
- Adoptive Siblings _____
- Stepsiblings _____
- Foster Siblings _____
- Extended Family (Such as Cousins) _____

What is your birth order among your siblings?

Example: If you are born first, you would enter "1." If you are born fourth, you would enter "4."

How many siblings are between you and your sibling with ASD in birth order (biological or adopted) in your family of origin?

Example 1: If you are 2nd born, and your sibling with ASD was 5th born, you would enter "1."

Example 2: If your sibling with ASD with 1st born and you were 2nd born, you would enter "0."

Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all sure	Several days	Over half the days	Nearly every day
Feeling nervous, anxiety, or on edge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to stop or control worrying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying too much about different things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble Relaxing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being so restless that it's hard to sit still	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming easily annoyed or irritable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling afraid as if something awful might happen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all
- Somewhat difficult
- Very difficult
- Extremely difficult

Please each question carefully, then **mark** one of the numbers to the right to indicate how you have felt or behaved **during the past week**, including today.

	RARELY OR NONE OF THE TIME (LESS THAN 1 DAY)	SOME OR A LITTLE OF THE TIME (1-2 DAYS)	OCCASIONALLY OR A MODERATE AMOUNT OF TIME (3-4 DAYS)	MOST OR ALL OF THE TIME (5-7 DAYS)
I was bothered by things that usually don't bother me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not feel like eating; my appetite was poor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I could not shake off the blues even with help from my family or friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble keeping my mind on what I was doing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt depressed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble keeping my mind on what I was doing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that everything I did was an effort.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt hopeful about the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought my life had been a failure.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt fearful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My sleep was restless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was happy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I talked less than usual.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt lonely.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People were unfriendly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I enjoyed life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I had crying spells.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt sad.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that people dislike me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could not get "going."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Would you like to be entered to win a \$25 Amazon gift card?

Yes

No

Please select the link below to enter your email for a chance to win one of four \$25 Amazon gift card in a raffle. The winners will be notified no later than 11/1/2022. If selecting the link does not activate it, please copy/paste the link into your browser.

https://northwestpsych.az1.qualtrics.com/jfe/form/SV_bNvK0JGT5IJfyFo

Thank you for participating in this survey.

If you have questions about this study, how your information will be used, please contact the investigator at Matthew.Arnold13@NorthwestU.edu. If you have concerns about this study, you may contact the investigator's faculty advisor at Leihua.Edstrom@NorthwestU.edu.

If this survey brought about any discomfort, emotional or psychological distress, you are encouraged to contact a professional for support.

For the King County 24-Hour Crisis Line, call 1-866-427-4747.

For the American Psychological Association Psychology Help Center, visit <https://www.apa.org/helpcenter/>.

To locate a counselor near you, visit www.psychologytoday.com and click the "Find a Therapist" link on the top menu bar.

Thank you!

TO END THE SURVEY, PLEASE SELECT THE BUTTON BELOW

Appendix C

Generalized Anxiety Disorder 7-Item (GAD-7)

GAD-7 Anxiety

Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid, as if something awful might happen	0	1	2	3

Column totals _____ + _____ + _____ + _____ =
 Total score _____

If you checked any problems, how difficult have they made it for you to do your work, take care of things at home, or get along with other people?			
Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Source: Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD-PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues. For research information, contact Dr. Spitzer at ris8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission.

Scoring GAD-7 Anxiety Severity

This is calculated by assigning scores of 0, 1, 2, and 3 to the response categories, respectively, of "not at all," "several days," "more than half the days," and "nearly every day." GAD-7 total score for the seven items ranges from 0 to 21.

0–4: minimal anxiety

5–9: mild anxiety

10–14: moderate anxiety

15–21: severe anxiety

Appendix D

Center for Epidemiologic Studies Depression Scale (CES-D Scale)

Page 1 of 1

Patient Name: _____ Date: _____

Instructions: Please read each question carefully, then **circle** one of the numbers to the right to indicate how you have felt or behaved **during the past week**, including today.

	RARELY OR NONE OF THE TIME (LESS THAN 1 DAY)	SOME OR A LITTLE OF THE TIME (1-2 DAYS)	OCCASIONALLY OR A MODERATE AMOUNT OF TIME (3-4 DAYS)	MOST OR ALL OF THE TIME (5-7 DAYS)
1. I was bothered by things that usually don't bother me.	0	1	2	3
2. I did not feel like eating; my appetite was poor.	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
4. I felt that I was just as good as other people.	0	1	2	3
5. I had trouble keeping my mind on what I was doing.	0	1	2	3
6. I felt depressed.	0	1	2	3
7. I felt that everything I did was an effort.	0	1	2	3
8. I felt hopeful about the future.	0	1	2	3
9. I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11. My sleep was restless.	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people dislike me.	0	1	2	3
20. I could not get "going."	0	1	2	3

Appendix E

Survey Respondent Qualtrics Raffle

Please enter a valid email to be entered to win 1 of 4 \$25 Amazon gift cards. (Example: "name@example.com").

Winners will be notified by 11/1/2021 and will receive the digital Amazon gift card via the email provided.
