

SISTER-TO-SISTER: A PHENOMENOLOGICAL STUDY OF WOMEN'S EXPERIENCES  
OF HAVING A SISTER WITH AUTISM SPECTRUM DISORDER BASED ON THE  
FEMALE AUTISM PHENOTYPE

by

William Gregory Carroll

Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Philosophy

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## ABSTRACT

Despite the amount of material currently available on autism spectrum disorder (ASD), little research has been done specifically on females with ASD. Several studies have looked at the various relationships that individuals with ASD have, but to date no known study has been done specifically on the sibling relationship between neurotypical and autistic sisters. In this study, through semi-structured interviews, four neurotypical women reported on their lived experiences of having a sister with ASD. Their accounts were analyzed using interpretative phenomenological analysis informed by the theory of a unique female autism phenotype. Six superordinate themes appeared in the work: social relationships, interests, internalizing problems, camouflaging, neurotypical sister's interaction with ASD, and autism and the family. Results supported the existence of a unique female autism phenotype in women with ASD and highlighted additional areas of interest in the interaction of autistic and neurotypical sisters. Findings suggest that neurotypical sisters and their families continue to struggle in conjunction with their autistic sister/daughter. These difficulties pose a unique challenge for the mental health field as ASD comes to be understood as a developmental disability with family-wide implications. Recommendations are provided for future researchers and practitioners regarding understanding and treating families of women with ASD.

*Keywords:* autism spectrum disorder, camouflaging, sister, female autism phenotype, interpretative phenomenological analysis

## **Dedication**

This dissertation is dedicated to my Grandmother, Marjorie L. Carroll, RN (June 17, 1929–August 16, 2014), who ignited a fire and passion in me for the professional care of others.

Additionally, I want to dedicate this dissertation and the fruit it bears to God my Father and the Lord Jesus Christ. Without the prompting of the Holy Spirit, I would have never begun this doctoral journey. As I have testified many times, God wanted this for me; I did not want this for myself. Walking in faith has brought me to this point, and walking in faith will see me through to the end.

God first, God only, God always. –*Will Carroll*

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So many people have made their own mark in my life, including ministers, teachers, and friends; however, none have shaped the way I look at and interact with the world quite like my wife, Shannon. I want to praise her for her patience and willingness to let me work first toward a master's degree and then this PhD. There has been so much stumbling and falling, but you were always patient with me, Shannon. Thank you.

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Finally, I want to acknowledge all of the professionals I work with at our clinics. You took a chance on me professionally and gave me a counseling job. You allowed me to pursue this PhD while investing hours of supervision in me. You have allowed me to lead within our organization. Thank you.

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**List of Abbreviations**

Autism Diagnostic Interview-Revised (ADI-R)

Autism Diagnostic Observation Schedule (ADOS)

Autism spectrum disorder (ASD)

Intelligence quotient (IQ)

Interpretative phenomenological analysis (IPA)

## CHAPTER ONE: INTRODUCTION

Autism spectrum disorder, or ASD, is a pervasive developmental disorder most often diagnosed in childhood (Mandell et al., 2005). Diagnosis of individuals with ASD is inconsistent across several domains including age, race, socioeconomic status, and gender (Mandell et al., 2002; Mayes & Calhoun, 2011; Thomas et al., 2012). Gender is a major factor in diagnosis; research has consistently shown that females are less often diagnosed with ASD than males by a ratio of 4:1 (American Psychiatric Association, 2013). The reason for this discrepancy based on gender is not known however, hypotheses exist, including the extreme male brain theory and a female autism phenotype (Baron-Cohen, 2002; Hull et al., 2020).

Research has repeatedly found that females with autism present differently than males in a variety of important areas (Duvekot et al., 2017; Lehnhardt et al., 2016; Whyte & Scherf, 2018). For example, Hull et al. (2020) identified four areas corresponding to a hypothesized female autism phenotype: difficulties with social relationships, relational interests, internalizing problems like anxiety, and efforts to appear neurotypical or “camouflage” (Bargiela et al., 2016, p. 3282).

In an attempt to better understand why females with autism present differently than males and at a lower rate, researchers have interviewed parents (Duvekot et al., 2017; Sutherland et al., 2017) and siblings of individuals with ASD (Orsmond & Seltzer, 2007; Orsmond et al., 2009). Sibling research conducted with brothers and sisters collectively has elucidated many important areas of ASD, including how siblings are used as caregivers and the sibling’s role in social situations with their brother or sister who has ASD (Ward et al., 2016). However, research using sisters specifically has not been conducted to investigate the existence of a unique female autism phenotype. To gain a fuller understanding of a possible female autism phenotype, qualitative

inquiry would be helpful to investigate if the four areas of difficulty with social relationships, restricted or repetitive behaviors or interests, internalizing problems, and camouflaging, are also important in the sibling relationship.

### **Background of the Problem**

There has been a significant increase in the number of individuals diagnosed with ASD in the past 30 years (Elsabbagh et al., 2012). Along with this increase in diagnoses, there is now a recognition that males are diagnosed with autism more often than females (American Psychiatric Association, 2013). Hull and colleagues (2017) hypothesized that this gender difference can be explained by a female autism phenotype. Hull et al. (2020) female autism phenotype is defined by significant differences in four areas: social relationships, relational interests, internalizing problems like eating disorders, and efforts to “camouflage” or take steps to appear neurotypical (Dean et al., 2017, p. 678). If these areas are taken under consideration, the number of females diagnosed with ASD may increase. The problem is that without a recognition of these traits as diagnostic, this change cannot occur. To promote an increased understanding of a female autism phenotype, these four pillars of Hull’s theory need to be further investigated. Therefore, an interpretative phenomenological analysis (IPA) research study was conducted using neurotypical sisters as reporters to further the understanding of a female autism phenotype.

### **Purpose of the Study**

The purpose of this qualitative research study is to ascertain what new insights women with a sister who has ASD can provide regarding females with ASD, based on the theory of a female autism phenotype. Qualitative research has been done with parents of children with ASD and siblings of males with ASD; however, no known qualitative research has been done on adult women a sister who has ASD. This gap in the literature creates a problem for diagnosis and

treatment because it means practitioners are forced to rely on data from research on child subjects or research on males to accurately diagnose and treat their female clients. Therefore, this study collected observations from adult subjects on their autistic sisters. The goal of this study is to better understand how women who have a sister with ASD are affected by their sisters' diagnosis and to increase the understanding of ASD in women by examining the lived experiences of their neurotypical sisters.

### **Research Question**

To help fill the gap in the research literature on females with ASD and to understand what women experience growing up with a sister who has ASD, the following research questions were developed for this study:

**RQ1:** In what ways does having a sister with ASD affect your relationship with her?

**RQ2:** What particular interests does your sister with ASD have that are unique to her?

**RQ3:** Does your sister with ASD have any other mental health diagnosis besides ASD?

**RQ4:** Does your sister with ASD act differently around others than she does around you, acting as if she does not have ASD?

**RQ5:** In what ways has having a sister with ASD made you who you are today?

### **Assumptions and Limitations**

#### **Limitations**

One limitation of many qualitative studies is a small sample size (Cridland et al., 2014; Gaffney, 2020; Kauschke et al., 2016). One of this study's limitations is a small sample size, however; a small sample is appropriate for IPA (Moustakas, 1994).

Another limitation of this research project is that the sample was not random; rather, it was a convenience sample made up of available persons from the clinic in which I work and the

clinics with which I am associated. Furthermore, the sample varied in age, consisting of women aged 18–35.

A final limitation was that no variables beyond gender and history of developmental disability were controlled for. All other variables were random, including age, level of education, and birth order. This limitation makes generalization inappropriate.

### **Assumptions**

This IPA study comes with several assumptions. I assumed most subjects would see their sister's disability as limiting, restricting, or an obstacle to their own lives and a problem for their families. Many pieces of phenomenological work on autism have investigated how life is different for those with family members with autism than for neurotypical families (e.g., Marciano et al., 2015; Petalas et al., 2009). For example, some results suggest that marriages are better because of the shared goal of helping a child with autism (Marciano et al., 2015).

Another assumption is that adults with sisters who have ASD will have taken one of two stands in adulthood: (a) having distanced themselves from their autistic sister or (b) having become a primary caregiver. I assume that women with sisters with ASD see their life as less important to their family because extra attention is often given to their sister (Ward et al., 2016). Research suggests that adults with a disabled sibling either try to find their own way in the world by leaving home or seek an altruistic path like their parents and become a caregiver for their sibling with ASD (Tomeny et al., 2017; Tozer et al., 2013).

### **Definition of Terms**

*Autism spectrum disorder:* A spectrum of disorders associated with neurodevelopmental delays leading to social impairments in communication and interaction as well as limited and/or repetitive interests or behaviors (American Psychiatric Association, 2013).

*Autistic:* A condition recognized by having been formally diagnosed with ASD using any of the normed measures including the ADI-R, ADOS, Childhood Autism Rating Scales, Gilliam Autism Rating Scales, or others.

*Camouflaging:* The use of purposeful behaviors, conscious or not, to appear neurotypical to others and/or attempts to limit or restrict behavioral tendencies to avoid the appearance of being autistic. Camouflaging includes participating in social activities like clubs or sports so as to appear neurotypical and restricting the desire to engage in repetitive behaviors like lining things up or demanding a specific order of activities (Dean et al., 2017; Dworzynski et al., 2012; Frazier et al., 2014; Hull et al., 2017; Lai et al., 2017).

*Female autism phenotype:* For the purpose of this dissertation, four major characteristics that are unique in type or intensity to females. These four characteristics are difficulty in relationships, including more conflict compared to males; restricted or repetitive interests that are relational in nature; internalizing problems such as anxiety, depression, and eating disorders, which are often diagnosed first; and attempts to present as neurotypical, a behavior that has come to be termed *camouflaging* (Bargiela et al., 2016; Hull et al., 2020).

*Hermeneutics:* The study of text for intentionality or meaning of the work, not just for what the work says (Moustakas, 1994).

*Ideography:* The scientific exercise of attempting to understand an experience or event in its own context such as the family or society (Allport, 1937).

*Interpretative phenomenological analysis (IPA):* An approach to qualitative psychological research that is informed by concepts and debates from three areas of philosophy: phenomenology, hermeneutics, and ideography (Smith et al., 2009).

*Phenomenology*: A qualitative research method developed in the 20th century by Edmund Husserl that focuses on the study of consciousness awareness in the human experience (Wertz, 2005).

*Sibling*: For the purposes of this dissertation, a biological sister of a female with ASD; that is, a sister who shares a biological mother and/or a biological father with a female with ASD.

### **Significance of the Study**

The potential impacts of this study include modified diagnostic and treatment modalities for females with autism and modified treatment approaches for families with an autistic daughter. Most of the research on treatment of autism has been done on males (Lai et al., 2012; Pfaff et al., 2011). The results of this work require the field of counseling to consider autism in females as different enough to justify different approaches to research, diagnosis, and treatment.

Much has been said about a male brain theory in the literature, but the results of this research will require future investigators to consider the autistic female brain (Baron-Cohen, 2002). This work will require researchers to reconsider the social components of autism, as females use social interactions for different reasons than males (Dean et al., 2017). Additionally, future researchers will need to consider restricted and repetitive behaviors that are not atypical as diagnostic (Sutherland et al., 2017). Future practitioners should look at problems like depression and anxiety as traits of a unique female autism phenotype. The findings of this study will help to reshape the way counselors diagnose ASD in females, specifically adult females. Finally, this research will require scientists to consider the purposeful efforts of females to hide their autistic symptoms in an attempt to appear neurotypical, also known as camouflaging (Bargiela et al., 2016).

## Theoretical and Conceptual Framework

To better understand the lived experiences of women who have a sister with ASD, an IPA was conducted. IPA postulates that researchers can understand how an individual makes sense of their world in a particular context (Smith & Osborn, 2008). Through the use of interviews, the researcher enters the world of the participant, gaining an understanding of the participant's unique experiences as well as of how the researcher interprets the participant's experiences. In this dissertation, the *world* is the lived experiences of the woman and the context is having a sister with autism.

Moustakas (1994), writing about meaning-making in phenomenological research, stated that in IPA, researchers construct a composite description of all of the meanings of the experience under investigation. The goal of this exercise is to write a universal description of the experiences of women who have sisters with ASD. In this work, I will make meaning of the experience of having a sister with ASD to describe in as many possible terms as necessary what it means to be the sister of a female with ASD.

Shinebourne (2011) stated that IPA finds its theoretical roots in phenomenology, hermeneutics, and ideography. Husserl viewed the phenomenological perspective as the meaning one derives from their own experiences, in other words, what one's experiences mean to oneself (Wertz, 2005). Hermeneutics investigates the meaning of the whole experience and the meaning of the parts of the experience in words or text (Moustakas, 1994). For this research, the hermeneutic investigation can be summarized by the question, "How is my whole life different because my sister has autism, and how are specific parts of life different because my sister has autism?" Ideography states that each person is unique and therefore their experiences are unique and valuable in their uniqueness (Allport, 1937). Ideography's function is to understand that

uniqueness in its own context, for this study, the women with a sister who has autism in the context of being a sister.

Underdiagnosis of autism in females is a problem because it guarantees that treatment will be delayed. Autism in girls is likely to go undetected for years longer than in males simply because females do not present exactly as males do (Hull et al., 2017). One of the main reasons for this underdiagnosis is that professionals do not have a good understanding of the unique traits of autism in females (Hull et al., 2020).

Hull et al. (2020) proposed a female autism phenotype to explain why females with ASD present differently than males in key areas of behavior. Evidence for this female autism phenotype includes unique difficulties in social relationships, including more conflicts in peer relationships than males and shorter relationships than males. Regarding restricted, repetitive interests, females appear to have interests that are less mechanical and more relational, though still restricted or repetitive. Females with ASD are more likely than their male counterparts to have internalizing difficulties like depression, anxiety, and eating disorders and are more likely to use camouflaging, including making appropriate eye contact or using prepared scripts to interact socially (Whyte & Scherf, 2018).

Camouflaging should not be understood as a coping mechanism only, as there are downsides to engaging in camouflaging. The research indicates that females who camouflage do so to appear neurotypical (Bargiela et al., 2016). This leads to a variety of internalizing and externalizing issues (Howe et al., 2015; Mandy et al., 2012). For example, in research conducted by Bargiela and colleagues (2016), participants reported that the cost of pretending to be normal included confusion about one's own identity and a physical drain from acting neurotypical. Fombonne (2020) reported that camouflaging highly correlates to social anxiety on the objective

measure Camouflaging Autistic Traits Questionnaire, suggesting a strong relationship between camouflaging and anxiety disorders. Additionally, Fowler and O'Connor (2020) found that camouflaging lead to delays in diagnosis and underestimates of support needed for females with ASD.

This research can benefit females with ASD by helping researchers and practitioners further define a unique female autism phenotype. With a better-defined phenotype for women, diagnoses may come more quickly and lead to treatment being offered sooner. Fusar-Poli et al. (2020) noted that an appropriate diagnosis of ASD may increase opportunities for the implementation of support systems in the academic realm as well as the occupational arena and likely help financially due to disability benefits.

### **Organization of the Remaining Chapters**

Chapter Two will provide a review of relevant literature on ASD, females with autism, siblings of individuals with autism. Chapter Three will cover research methods, including research design and participant selection along with data processing and analysis. Chapter Four will present the results of this IPA, and Chapter Five will present a summary and discussion of findings along with recommendations.

### **Chapter Summary**

Adult women with sisters who have ASD are an untapped source of information about female autism. These adults can provide a wealth of information about their sisters' relationships with them, their sisters' restricted or repetitive interests, internalizing problems such as eating disorders, and their attempts to appear neurotypical (Hull et al., 2017). This chapter addressed the assumption that males and females with ASD present similarly, though research indicates that they do not. It defined terms for this study including *female autism phenotype*,

*camouflaging*, and *IPA*. This chapter considered the importance of this research, as it furthers the understanding of ASD in females, leading to timely and appropriate diagnosis of ASD. Finally, this chapter provided support for the use of IPA as a well-established means for studying women who have a sister with ASD.

## **CHAPTER TWO: LITERATURE REVIEW**

The purpose of this chapter is to review the current literature on two groups of people: females with ASD and siblings of individuals with ASD. First, this chapter will discuss the literature on females with ASD and the ways they present differently than males with ASD. This discussion will be based on the theory of a unique female autism phenotype. Secondly, this chapter will review the effects of having a sibling with ASD on individuals. Current research will be discussed, including studies on how the individual is affected interpersonally, in their private world, and socially.

### **Neurodevelopmental Disabilities and Autism Spectrum Disorder**

The Americans with Disabilities Act of 1990 defines disability in a person as any “physical or mental impairment that substantially limits one or more major life activities” (p. 7). Developmental disabilities are lifelong conditions that affect an individual physically, mentally, emotionally, intellectually, or behaviorally (American Psychiatric Association, 2013; Zablotsky et al., 2019). Examples of neurodevelopmental disorders including specific learning disorders, attention deficit/hyperactivity disorder, and ASD.

ASD is a neurodevelopmental disorder most often diagnosed in childhood (American Psychiatric Association, 2013). Two prominent presenting symptom clusters are evident in individuals with ASD. The first is in the areas of social communication and social interaction. Individuals with ASD often present with delays in both verbal and nonverbal communication. They have difficulties in establishing or forming relationships and understanding how others form relationships. There are also often deficits in understanding the emotional weight of relationships such as others’ feelings and socially appropriate behaviors including eye contact.

The second symptom cluster found in individuals with ASD is in the area of restricted and repetitive activities, behaviors, or interests (American Psychiatric Association, 2013). Stereotyped movements, repetitive use of items, and stereotyped speech (e.g., echolalia) are common symptoms of ASD. Additionally, inflexibility and a strong desire for predictable routines and familiar environments as well as sensitivity to external input such as light, sound, or temperature are symptoms of ASD.

ASD occurs in one in every 59.5 children in the United States and is four times more common in males than females (Baio et al., 2018). Because of this perceived discrepancy, researchers have begun to ask why there is a difference between males and females (Lai et al., 2012). Questions concerning why males present as and are diagnosed with ASD more often than females abound (Baron-Cohen, 2002; Hull et al., 2017); one theory is that females with ASD present with a unique female autism phenotype (Lehnhardt et al., 2016).

The term *phenotype* refers to the observable, physical characters of an individual (Mader, 1998). In regard to ASD, *phenotype* refers to the observable, behavioral characteristics of an individual such as echolalia or fixation on parts of an object. Phenotype is important because no single biomarker completely explains ASD, making phenotype the only means by which ASD may be diagnosed (Goldani et al., 2014). As a developmental disorder, ASD is often diagnosed using observation schedules and interview forms; specific examples include the ADOS and the ADI-R. These instruments allow the professional to understand what caregivers and peers are seeing in the individual's life, providing long-term data on phenotype.

Additionally, treatment is often based on phenotype. Observed restricted or repetitive behaviors are modified using approaches such as applied behavior analysis (Matson et al., 2012).

Phenotype informs both the diagnosis of ASD and the treatment of ASD symptoms, making it critically important to understand.

### **Difference Between Males and Females with ASD**

ASD varies phenotypically by sex both diagnostically and in important nondiagnostic domains such as self-harm and suicidality (Lai et al., 2011). Frazier et al. (2014) noted that being male is one of the most widely recognized risk factors for the diagnosis of ASD because males are diagnosed three to four times more often than females. Additionally, females tend to present differently in both diagnostic and nondiagnostic areas (Hull et al., 2017). This difference often leads to females being diagnosed later than males (Howe et al., 2015). Because of ASD's phenotypical variation between the sexes, there is a need to understand these differences so clinicals can provide an accurate diagnosis and better, more effective treatment for females diagnosed with ASD. A greater understanding of the cognitive, social, and behavior characteristics that are unique to females with ASD will help define a unique female autism phenotype.

### **Cognitive**

#### ***Intelligence Quotient***

According to the Center for Disease Control's (2020) *Surveillance Summaries*, the ratio of boys to girls with ASD is 4.3:1. Additionally, Dworzynski et al. (2012) stated that the ratio of boys to girls with high-functioning ASD is 10:1, with high functioning defined as an IQ above 70. These statistics imply that most females with ASD also have cognitive impairments (Volkmar et al., 1993). In a first-of-its-kind study assessing intelligence in ASD using modern measures, Lord et al. (1982) found that females with ASD scored lower on standardized intelligence tests than their male counterparts. Generally, Goldstein and Saklofske (2010) noted,

adults with ASD who are high functioning scored more highly on perceptual reasoning than verbal skills on Weschler intelligence measures. Holdnack et al. (2011) found significant deficits in the comprehension subtest of the Weschler Adult Intelligence Scale IV and on tests of processing speed for adults aged 16 to 40 with ASD. Research has found that ASD symptoms in some cognitive domains vary by sex (Lawson, 2019). Two studies have found that females with ASD showed lower cognitive abilities than on the ADI-R (Dworzynski et al., 2012; Frazier et al., 2014). Another study, which used the Child Behavior Checklist, revealed that females ages four to 18 of average intelligence with ASD had more thought problems than matched-pair males with ASD (Holtmann et al., 2007). Finally, Tsakanikos et al. (2011) found that female adults with ASD with below average IQs were more likely to be diagnosed with dementia, while their male counterparts were more likely to be diagnosed with a personality disorder.

### *Language*

Language is an important component of the cognitive domain, as seen in work by Lai et al. (2011), who found that females with ASD and a history of language delays had significantly lower performance IQ and marginally lower verbal IQ compared to females ASD and no history of language delays; this finding was not true of males with ASD. Holdnack et al. (2011) found deficits in language across all domains of the Weschler Adult Intelligence Scale IV for adults with ASD. This finding suggests that language delays, a diagnostic factor in ASD, are more closely tied to the female phenotype of ASD than to the male type. Specifically, language delays appear to predict lower IQ in females but not in males (Howe et al., 2015). Lawson (2019) noted that the female executive functioning advantage is likely a contributor to camouflage, as reported by Dean et al. (2017) and Rynkiewicz et al. (2016). Research has also found that females with

ASD have lower language abilities than males, as evidenced by scores on the ADI-R (Dworzynski et al., 2012; Frazier et al., 2014).

## **Social**

Impairment in social functioning is a key feature of ASD. People with ASD typically struggle with peer interactions and isolation. Howlin and Asgharian (1999) reported that the earliest concerns of parents in their study of children with ASD were communication and social and behavioral problems. Research has found that both males and females with ASD struggle significantly with social interaction; however, females experience more social problems than males (Holtmann et al., 2007). For example, Frazier et al. (2014) found that females with ASD had greater overall impairment than males, which manifested itself in more social communication/interaction symptoms of ASD than same-age males. However, findings are mixed across studies, likely reflecting varying measures used, age of subjects, and subjects' IQ. Holtmann et al. (2007) postulated that the sex differences observed and reported might be caused by socialization, sex role models, and a difference in the rearing of males compared to females.

Dean et al. (2017) found that females with ASD presented different social behaviors than males with ASD. Specifically, they found that females with ASD were more likely than males to keep in close proximity to peer groups during unstructured play time and to move between activities during the same time. On the other hand, Dean and colleagues (2017) found that males with ASD were more likely to self-isolate. This finding means that females are less likely to be diagnosed with ASD, as they would not immediately meet the criteria for difficulty in social situations, an example of how females with ASD camouflage.

More subtle indicators of ASD in girls and women may include excessive shyness or bossiness, being overly controlling in interpersonal relationships, or being excessively driven or

perfectionistic (Lai & Baron-Cohen, 2015). Verbal problems in females with ASD might include talking loudly and saying things that others might consider inappropriate for the social situation. Social problems in females with ASD may include tremendously high standards for friends such as extreme loyalty, being exceedingly clingy with certain people, or making social behaviors regimented or formalized.

### ***Communication Deficits***

The first overarching symptom presentation in the diagnosis of ASD is deficits in social communication and social interaction. Research into communication of individuals with ASD indicates that females present with more communication deficits than males (Hartley & Sikora, 2009). Dworzynski et al. (2012) found that females with ASD had few social autistic-like traits and more communication autistic-like traits than males with ASD. This finding is in line with the work of Lord et al. (1982), who found that girls with ASD scored significantly lower on measures of receptive vocabulary than their male counterparts. In an interesting and revealing study about communication and ASD, Kauschke et al. (2016) investigated boys' and girls' ability to tell stories. The authors found that there was not a significant difference between autistic boys' and girls' ability to tell their stories. In fact, the only between-groups difference was that girls with ASD used fewer explicit references to time. A single-group comparison, however, found that girls with ASD used fewer words to describe emotions than typically developing female peers. When compared to boys with ASD, girls with ASD produced significantly more casual explanations for internal states. In other words, girls with ASD were more likely than boys with ASD to explain why someone thought or felt the way they did.

### *Friendships*

There is far less known about friendships of girls diagnosed with ASD compared to their male counterparts (Sedgewick, Hill, & Pellicano, 2019). However, Sedgewick, Hill, & Pellicano, (2019) found that girls with ASD reported having close friends or even a best friend, contrary to popular stereotypes, though they reported fewer friends than their neurotypical peers. These same results suggest that these girls' friendships are more helpful, more secure, and closer than similar relationships for males. Also, the foundation of friendship for girls with ASD appears to be the same as for neurotypical girls: emotional sharing and time together. The differences between neurotypical girls and girls with ASD were that girls with ASD simply had fewer close friends than neurotypical girls and struggled to maintain those relationships. In this study, girls reported that their closest friendships were likely to be neurotypical girls. On another note, boys and girls with ASD shared a highly variable attitude toward dating.

Sedgewick, Crane, et al. (2019) found that girls with ASD experienced more relationship-based conflict than boys with ASD. During conflict among peers, girls with ASD tended to take an all-or-nothing approach, leading to greater conflict. Also, conflict was categorically different, with boys with ASD reporting overt difficulties as conflict and girls speaking of social interactions, like being talked about behind their backs, leading to conflict. Girls with ASD did not mention competition between peers, suggesting that they were unaware of the attempts to one-up each other occurring within their social environment.

Finally, Sedgewick, Crane, et al. (2019) found that women with ASD were more likely than neurotypical women to be exploited, likely due to their inability to fully understand others' intentions and social situations. This exploitation was most common in social and sexual situations.

## **Behavioral**

As previously stated, a diagnosis of ASD is based on a phenotypic presentation, which is observed by a reporter or a professional (American Psychiatric Association, 2013; Lai et al., 2011). As with many developmental disorders, there is not a single biomarker for identifying individuals with ASD (Goldani et al., 2014). For this reason, professionals look for phenotypes of ASD, like repetitive and/or stereotyped behaviors and delays in communication. Research has consistently found a similar pattern of development across the lifespan in males and females with ASD (Dworzynski et al., 2012; Hartley & Sikora, 2009; Holtmann et al., 2007). However, it has been argued that females present differently in key diagnostic and nondiagnostic areas and that these differences are one reason males are diagnosed four times more often than females (Holtmann et al., 2007). Part of this argument is based on the finding that females with ASD are more likely to report more severe autistic traits than males (Lai et al., 2011).

### ***Stereotyped, Restricted, and Repetitive Behaviors or Interests***

The second overarching symptom presentation in ASD is limited interests or restricted behaviors that are inconsistent with the individual's age. In regard to this symptom and its presentation in males and female, Van Wijngaarden-Cremers et al. (2014) found that generally, females with ASD present with fewer stereotyped, restricted, and repetitive behaviors than their male counterparts, and Frazier et al. (2014) found that females with ASD had fewer restricted interests than males. Mandy et al. (2012) found that females aged three to 18 years had fewer repetitive stereotyped behaviors than same-age males with high functioning ASD, and Knutsen et al. (2019) found based on clinical observation that both younger higher-functioning females with ASD and older, lower-functioning females with ASD showed less in restricted and repetitive behaviors than younger low-functioning females with ASD. These findings support the

current research that shows that males and females with ASD present differently in key diagnostic areas (McFayden et al., 2020). Hartley and Sikora (2009) stated that the finding that males present with more stereotyped, restricted interests and repetitive behaviors than girls is the most consistent diagnostic sex discrepancy found in the literature. Similarly, Lawson (2019) stated that there is enough evidence for a female ASD profile from this research on restricted and repetitive behaviors to consider sex a moderator in diagnosis.

Another diagnostic feature of ASD is unusual sensory issues (American Psychiatric Association, 2013). Research has found that females experience more sensory issues over their lifetime than their age/IQ matched male counterparts (Lai et al., 2011). Lai and colleagues defined sensory issues based on the ADI-R's pool of questions about unusual sensory interests, undue general sensitivity to noise, and abnormal, idiosyncratic, negative responses to specific sensory stimuli.

### ***Nondiagnostic Behaviors***

Nondiagnostic behaviors continue to be a point of interest in ASD research. For example, Howe et al. (2015) found that females with ASD have less severe internalizing problems than males. Dworzynski et al. (2012) found that girls with ASD were more likely to have behavioral issues such as hyperactivity, conduct problems, peer relationship problems, and anxiety than males with ASD. Similarly, Hartley and Sikora (2009) found that girls present with more sleep problems than age-matched boys. Females with ASD also have a more pronounced anxious or depressed affect than their male counterparts (Lai et al., 2011). Holtmann et al. (2007) found that autistic females with an average IQ presented with more attentional problems than matched males. Additionally, Holtmann et al. (2007) and Howe et al. (2015) found that females had more externalized problems than same-age males with ASD. Finally, abnormal eating behaviors are

more common in ASD populations, including food refusal, selective eating, and pica (Råstam, 2008). Pooni et al. (2012) found that children and young adults who suffer from early-onset eating disorders also had elevated traits of ASD, specifically repetitive and stereotyped behaviors.

### ***Adaptive Behaviors***

Adaptive behaviors are understood to be those behaviors an individual engages in to cope with the stress of life or a specific problem. How an individual modifies their behavior to deal with a problem or how they change the way they think about the world is adaptation. Adaptation is seen, for example, in camouflaging, as reported by Dean et al. (2017). Frazier et al. (2014) and Howe et al. (2015) found that females with ASD had poorer adaptive functioning than males with ASD as well as more lethargy and more self-injurious behaviors. They also found that females had an increased number of problem behaviors based on parent reports, specifically externalized problems and irritability. Banach et al. (2009) found that females with ASD from families where there were no other siblings with ASD had greater impairment in communication than males from the same family type. Communication was considered an adaptive behavior in this study because IQ was not controlled for. Mahendiran et al. (2019) found that females with ASD had poorer adaptive functioning in the three domains of social skills, leisure skills, and communication skills at older ages, 12 and 13 years, than at younger ages, seven and eight years. The authors stated that this may be the result of more complex and significant social pressures as females enter adolescence or a comorbid disorder manifesting in adolescence.

### ***Self-Harm and Suicidal Behaviors***

Self-harming behaviors are a major issue in ASD. The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; American Psychological Association, 2013) includes skin picking,

hair pulling, and head banging, along with the more well recognized self-harming behaviors like hitting, biting, and scratching oneself as self-harming behaviors. Research has found that up to 50% of adults with ASD engage in some form of self-harming behavior and that women, more than men, engage in nonsuicidal self-harming behaviors (Maddox et al., 2017). This same research found that on average, adults with ASD began nonsuicidal, self-harming behaviors by 12.7 years of age.

A significant factor in self-harming behaviors was the management of suicidal desires (Maddox et al., 2017). Adults reported harming themselves in an effort to hurt someone else, to shock someone else, or because they observed someone else hurting themselves. Cohen et al. (2010) studied aggression in individuals with intellectual disabilities and with ASD. They found that females with ASD were more likely than males with ASD to make self-hating statements. They also found that females with ASD were more likely than females with intellectual disabilities to engage in self-harming behaviors. The results of their study suggest that women with ASD act out anger in ways that are consistent with their verbal abilities. The researchers also noted that the degree of self-deprecation and self-harm decreased significantly after the fifth decade of life (Cohen et al., 2010). Antezana et al. (2019) found that women with ASD were more likely to report pulling their hair and scratching themselves than males with ASD. Additionally, Duerden et al. (2012) found that females were more likely to engage in self-injurious behaviors than males, though the difference was not statistically significant. They found that the older the person was, up to age 19, the more severe the self-injurious behaviors were. This finding may indicate that a person with ASD does not get the same level of stimulation from less painful forms of sensation, or they may suggest that the stress of life increases with age.

Additionally, adults with ASD are at an increased risk of suicidal behaviors (Fowler & O'Connor, 2020; Hedley et al., 2017; Hirvikoski et al., 2016; Kirby et al, 2019). Cassidy et al. (2014, 2018) found that adults with ASD were more likely to have suicidal ideations and to attempt suicide than adults from the general population. They found that over a third of people with ASD had planned and/or attempted suicide. Specifically, they found that women with ASD, aged 16 to 74, were more likely than men with ASD to experience depression, have suicidal ideations, and make suicide attempts. Fowler and O'Connor (2020) found that females were more likely to experience depression and engage in suicidal behaviors if they had received a later diagnosis of ASD, that is, after nine years old. Hirvikoski et al. (2016) found that females with ASD were far more likely than their male counterparts to complete suicide. Additionally, Cassidy et al. (2014, 2018) found that suicide attempts increase with age for women with ASD but not for men with ASD. The reasons for the suicide attempts vary, but Cassidy et al. (2018) identified a variety of predictors of suicide attempts, including self-harming behaviors and unmet needs for support and assistance. Interestingly, the researchers found that camouflaging, mentioned earlier, was a significant predictor of suicidality.

### ***Sexual Behaviors***

Despite their social deficits, many individuals with ASD experience a desire for sexual interaction (Bush, 2019). Fernandes et al. (2016) found that of males and females with ASD with accompanying intellectual impairments, 60% had an interest in sexual relationships. This same research found that half of this sample reported interest in same-sex relationships. Additionally, 32% of individuals reported no sexual interest at all. More specifically, Bush (2019) found that 13% of their female-only sample reported being asexual. Bush (2019) also found that a majority of the participants in her female-only study reported lower overall sexual desire than

neurotypical controls. The researcher found that women with ASD reported less sexual consciousness, that is, thoughts, feelings, and sensations. Also, sexual monitoring, which includes awareness and concern about one's sexual presentation to others, was lower in females with ASD.

On the other hand, Bush (2019) found that sexual satisfaction for individuals with ASD was comparable to that for neurotypical individuals. This finding may suggest that young women aged 18 to 30, with and without ASD, are not so different in their sexual experiences. Additionally, the researcher found that sexual desires and engagement and thoughts about sexuality were important to both neurotypical and autistic women. It would appear that women with ASD are no different from women without ASD in these sexuality-related variables. Finally, Bush (2019) found that the sexual desire, behaviors, and consciousness increase with age for females with ASD. The author noted that the study was not longitudinal; however, the results based on age indicated that the older the women were, the greater their sexual desire was, the more sexual behaviors they engaged in, and the more they thought about sexuality.

### *Camouflage*

Camouflaging is performing a set of social behaviors and restricting symptom presentation to allow the individual with ASD to go undetected or underdetected by parents, peers, and professionals (Dean et al., 2017; Lehnhardt et al., 2016; Rynkiewicz et al., 2016). Camouflaging is the coping strategy that allows an individual with ASD to present as neurotypical in a variety of social settings (Lai et al., 2017). These efforts to appear neurotypical are culture bound, whether that be a work culture or a family culture (Baird, 2020). Camouflaging is independent of sex, age, and IQ (Lai et al., 2017).

Research has consistently found that females with ASD use more camouflage than their male counterparts (Cassidy et al., 2018; Hull et al., 2017; Lai et al., 2017). By way of example, Aggarwal and Angus (2015) found that ASD symptoms were far less likely to be recognized in girls than boys because of multiple factors, including that boys are more likely to present with overt symptoms of ASD. In another study, Dean et al. (2017) found that girls with ASD spend a significant amount of their free time at school oscillating between joint engagement with neurotypical girls and isolation, that is, floating in and out of peer engagement as they were being ignored by fellow students. Numerous examples of camouflaging efforts have been noted in the literature, including forcing oneself to make eye contact and mimicking others' words and mannerisms (Hull et al., 2017; Lai & Baron-Cohen, 2015).

The practice of camouflaging comes at a cost, however. Camouflaging requires an incredible amount of mental effort, which may lead to emotional dysregulation and possibly increased pathology (Lai et al., 2011). Camouflaging becomes particularly serious when it leads to a delay in diagnosis (Tubío-Funqueiriño et al., 2020).

### **Pulling it Together: Female Autism Phenotype**

Lehnhardt et al. (2016) proposed a female autism phenotype based on intelligence, executive functioning, primary and secondary pathology (ASD and depression), theory of mind, and social characteristics. Bargiela et al. (2016) followed with their own proposal for a female autism phenotype. They proposed that camouflaging, internalizing problems like depression, greater social motivation, and better nonverbal communication define their female autism phenotype. In support of this position, they found that a large portion of their sample, 93%, suffered from an anxiety disorder. Though the definition of a female autism phenotype has been further refined since these studies were published (e.g., Hull et al., 2020) certain traits from the

original works remain, including camouflaging, secondary pathology such as depression and anxiety, and social behaviors.

### **Siblings of Individuals With Autism**

Sibling relationships are unique within human relationships in that they are frequently children's first peer relationship and individuals' longest lifetime relationship (Cicirelli, 1995; Orsmond et al., 2009; Sage & Jegatheesan, 2010). It is through these sibling relationships that behaviors like collaborative play and social skills are observed and practiced (Dunn, 1988; Knott et al., 1995, 2007). Interests are shared and ways of being are often explored with siblings. The sibling relationship serves as grounds for many social, emotional, and interpersonal experiments.

The sibling relationship changes in several ways when a disability is present (Knott et al., 1995). Disabled siblings may learn differently, learn more slowly, or lack certain motivations altogether. The disabled sibling may require a higher level of attention and care, leading to less opportunity for reciprocal practice or social learning with their neurotypical sibling. The sibling with a disability may create more stress in the family, taking attention away from other members of the family (Shivers et al., 2019). In later life, individuals who grew up with a disabled brother or sister may take on the major caregiving role when their parents are no longer able to provide for the disabled individual (Chen & Lukens, 2011). Additionally, while the parents or primary caregivers are still able to provide care, neurotypical siblings often provide emotional support to that parent or caregiver (Benderix & Sivberg, 2007; Zatzlow, 1982).

The literature on siblings of individuals with ASD goes back to the 1980s (e.g., McHale et al., 1986), but research on individuals with siblings who have a disability goes back even further. The study of siblings of individuals with disabilities, including ASD, finds its roots in the study of parents of children with a disability (Sutherland et al., 2017). Researchers in the 1980s

had gathered an incredible amount of information from parents but were missing information from the disabled person's peers, role models, playmates, and friends: their siblings. In the research of neurotypical siblings of individuals with a disability researchers began by asking neurotypical siblings about well-being and factors such as family size and birth order. This work led to the development of a body of quantitative and qualitative research examining how the neurotypical sibling is affected by their brother or sister with ASD (e.g., Shivers et al., 2017).

Research on siblings of individuals with ASD has included neurotypical siblings as young as five years old, and most often, research samples include individuals up to their late teen years, with few exceptions (Bågenholm & Gillberg, 1991; Orsmond et al., 2009; Petalas et al., 2012). However, to date, very few pieces of research have been conducted exclusively with adult siblings (e.g., Burton & Parks, 1994; Tomeny et al., 2017). This lack of sample data is likely the consequence of convenience sampling and the popularity of studying individuals with ASD in childhood. However, adult siblings of individuals with ASD may provide an untapped wealth of information for research and practice. Adults may have greater insight into their own behaviors as well as the behaviors of others when compared with teenagers or young children. Additionally, adults have had more time to explore their own feelings about having a sibling with ASD. Therefore, adult siblings of individuals with ASD will likely be able to provide unique insights into their sister's behaviors.

In studies conducted on neurotypical siblings of individuals with ASD, samples are most commonly a mix of male and female subjects (e.g., Kaminsky & Dewey, 2001; Ross & Cuskelly, 2006; Shivers et al., 2017, 2019). Further, the siblings being discussed are usually a mixed group as well, both males and females (e.g., Kaminsky & Dewey, 2001; Ross & Cuskelly, 2006). Yet the individuals with ASD being discussed are most often male, with few studies noting the ratio

of male-to-female siblings (e.g., Hwang & Charnley, 2010; Mascha & Boucher, 2006). This phenomenon is likely the result of convenience sampling in the research. However, there does exist a small body of research on individuals with brothers who have ASD (e.g., Petalas et al., 2009; Sage & Jegatheesan, 2010). These studies used qualitative methods to examine the relationship between the brother with ASD and their siblings. Both studies found that even among siblings of the same boy, reports of lived experiences could vary significantly. This variation raises several questions, including the effect the gender of the neurotypical sibling may have on lived experience. To date, there has been no known research conducted exclusively on the adult siblings of females with ASD.

### **Experiences of Siblings of Autistic Individuals**

Siblings may provide unique insight into the autism spectrum in females, as they are often the closest, nonprimary caregiver in the female's life. Their understanding of the syndrome is personal, and it is not concerned with diagnostic accuracy. This lay point-of-view is distinctive and therefore can provide valuable information.

To assess the experiences of siblings of individuals with ASD, researchers have used both quantitative and qualitative research methods. Methods such as semistructured interviews are common among qualitative experiments, while instruments assessing the sibling relationship or the sibling's well-being are common in quantitative work (Orsmond et al., 2009; Petalas et al., 2009). Sibling research has typically focused on the lived experiences of siblings of individuals with ASD (Petalas et al., 2009) or on the relationship between neurotypical and autistic siblings (Kaminsky & Dewey, 2001), and in some cases, on the social and familial consequences of having a sibling with ASD (Hwang & Charnley, 2010; Sage & Jegatheesan, 2010). For example,

research by Reagon et al. (2006) found that neurotypical siblings can effectively intervene in the development of their brother or sister with ASD via play.

Lived experiences of siblings of individuals with ASD are typically divided into two broad areas, the positive impact and the negative impact of having a sibling with ASD (McHale et al., 1986; Ward et al., 2016). Research has consistently found that siblings of individuals with developmental disorders, including ASD and intellectual impairments, are negatively impacted by the disorder. This negative impact often leads to social-emotional problems, behavior problems, and interpersonal problems (Bågenholm & Gillberg, 1991; Mascha & Boucher, 2006; Neece et al., 2010; Petalas et al., 2009). Kaminsky and Dewey (2001) found that neurotypical individuals with autistic siblings reported less intimacy, less nurturance, and less prosocial behavior within the sibling relationship, while Ross and Cuskelly (2006) reported that 84% of their respondents noted aggression as the most common stressor in the sibling relationship. Similarly, Ward et al. (2016) noted that sisters often talked about the difficulty in communicating and interacting with their younger sibling with ASD. Sisters also reported burnout, a lack of appreciation, and receiving criticism when trying to help (Cridland et al., 2016). Ward et al. (2016) noted worry from the neurotypical sister when they were in social situations and having to pay extra attention to the sibling with ASD. Orsmond et al. (2009) reported that as siblings of autistic individuals become adults, they lose support from parents and friends but likely gain support from other important relationships such as partners.

On the other hand, research findings have indicated a host of positive qualities related to having a sibling with ASD or another development disorder. Positive qualities have included the neurotypical sibling being nurturing, having a positive perspective of their family, and having a sense of wonder or respect around their sibling with ASD (Kaminsky & Dewey, 2001; Mascha &

Boucher, 2006; McHale et al., 1986). Research has also noted that siblings of children with ASD report positive impacts on the family (Hodapp et al., 2010; Ward et al., 2016). Neurotypical individuals report that their autistic sibling is a pleasure to be around, is happy and loving, and teaches them things like empathy and compassion. Cridland et al. (2016) noted that sisters reported feeling good about helping their brother who has ASD and those around him. Ward et al. (2016) noted that positive comments usually came from older siblings, 13 years old and older. These feelings and ideas are likely the result of maturity and reflection. Also, greater understanding about ASD appears to create a good relationship in siblings. Roeyers and Mycke (1995) found that adolescents aged eight to 15 with more knowledge about ASD reported a more positive relationship with their sibling with ASD. Research conducted by Orsmond et al. (2009) found that the autistic-neurotypical sibling relationship remains stable into adulthood. This relationship is moderated by the quality of the adolescent relationship of the pair. Additionally, Orsmond and colleagues (2009) found that the larger the family, the more positive the relationship is between the autistic and neurotypical siblings. This is likely because the neurotypical sibling feels less of a burden to care for the siblings with ASD; responsibility is shared. The authors also noted that adults engaged in more shared activities with their autistic brother or sister if their sibling with ASD was younger than them. This may be due in part to a feeling of control by the neurotypical adult that they did not have as a child or a felt responsibility on the part of the adult to help the family now that they themselves are an adult.

### **Sibling Relationship**

As neurotypical siblings age, the amount of engagement with the autistic sibling changes based on the gender of the pair. For example, Orsmond et al. (2009) found that for adults, if the relationship is between two sisters, there is more interaction between the siblings, but if the pair

is a neurotypical brother and autistic sister, then there is far less interaction. Additionally, Cridland et al. (2016) found that sisters reported that their responsibilities had become more prominent as their autistic brother grew older, specifically in educational and social matters.

### **Family**

Research on the familial and social consequences of having a sibling with ASD tends to focus on the neurotypical sibling's felt obligation to protect the sibling with ASD from the world, to serve as an additional parent (parentification), and to prevent the sibling with ASD from hurting themselves or others, which could reflect poorly on the family (Barak-Levy et al., 2010; Benderix & Sivberg, 2007). This was particularly true for female neurotypical siblings who were often assigned the task of caregiving in the absence of the parents (Cridland et al., 2016). To this point, Ward et al. (2016) found that neurotypical siblings received less attention from their parents and were expected to shoulder more responsibility than their brother or sister with ASD. Similarly, adult participants in a study by Burton and Parks (1994) felt that they were more responsible because they grew up with a sibling who has ASD. In fact, Burton and Parks concluded that there are tangible benefits of growing up with a sibling with ASD, including improved self-esteem and locus of control. By contrast, adolescents in a study by Benderix and Sivberg (2007) reported not wanting to ask friends to visit their home because of their sibling with ASD, fearing what he or she might do in the presence of their friends. Also, respondents noted a felt need to take care of their sibling with ASD and to not burden their parents with their own needs. In a study by Barak-Levy et al. (2010), neurotypical children with a brother with ASD were found to participate in fewer extracurricular activities. These same children had poorer social skills and poorer school performance than neurotypical children without an autistic sibling.

Barak-Levy et al. (2010) argued that in a family with a disabled child, the disability affects not only the child, but also affects the parent and parenting style, thus affecting the entire family system. It is evident that ASD has a far-reaching effect on a family system that includes an individual with ASD. Research on family stress tends to focus on stress from inside the family. For example, Benson and Karlof (2008) found that increased involvement by parents in the education of the individual with autism was related to a positive adjustment by the neurotypical sibling. Additionally, they found that stressful life events, as measured by the Parenting Stress Index, and the atmosphere at home predicted prosocial behavior in the neurotypical child. Shivers et al. (2017) found that behavior problems among children with ASD were not the sole contributor to increased sibling stress. There appeared to be a group membership factor; being a part of a family that included a child with ASD increased stress. Even in adulthood this family stress is observed. Nuttall et al. (2018) found that adults aged 18–25 with siblings who were autistic reported less of an intention to provide care for their autistic sibling than same-age peers who had a sibling with Down syndrome. Additionally, the researchers found that typically developing siblings engaged in higher levels of parent-focused parentification than sibling-focused parentification during childhood; in other words, the parents required more of the neurotypical sibling's effort than the autistic sibling did. The parents were using the child to get their own needs met. The authors predicted that this would negatively affect caregiving in the future, that the typically developing sibling would not want to help the sibling because with ASD because of all they have already done for the parents. Finally, Benson and Karlof (2008) found that a strong marriage, a cohesive family, and low parental conflict were major predictors for neurotypical sibling's health within families with a child with ASD.

## Chapter Summary

Research has consistently found that females with ASD present differently than males with ASD. Additionally, research has found that siblings of individuals with autism are good reporters of their experiences growing up with an individual with ASD. Because of the significant difference in number of females and males diagnosed with autism, little is known about the experiences of family members of females with ASD. More specifically, there is a gap in the literature in the area of experiences of siblings who grew up with a sister with ASD. The benefits of researching the lived experiences of adult females with ASD include providing a better understanding of a unique female autism phenotype, as well as improved treatment modalities specifically for women with ASD.

## **CHAPTER THREE: METHODS**

This chapter includes a description of the research design and methods used in this IPA. The goal of this IPA research study is to analyze the experiences of adult females who have a sister with ASD using a female autism phenotype as the theoretical basis. The understanding that the experience of having a sister with ASD is unique and that females diagnosed with ASD are rare guides this IPA research. A woman's perception on her autistic sister may provide new insights into autism generally and specifically into a female autistic phenotype.

### **Research Design**

This research was conducted using the qualitative approach IPA (Smith & Osborn, 2008). This qualitative approach was chosen because a female autism phenotype is a relatively young theory in autism research and is not well defined (e.g., Bargiela et al., 2016; Hull et al., 2017, 2020; Lehnhardt et al., 2016). Additionally, autism research with only females is less common than research with a mixed group (Gaffney, 2020), and research with all females on females with autism is lacking in the literature (e.g., Cridland et al., 2014). The goal of IPA research is to understand the participant who is trying to make sense of their own personal world.

### **Interpretative Phenomenological Analysis**

IPA employs purposeful sampling (Smith & Osborn, 2008), which includes a homogeneous sample, as analysis requires individuals with very similar backgrounds. IPA has as its goal the understanding of the subjective experiences of individuals under study. The intention of the IPA is to focus on the personal from the perspective of the one experiencing the event (Marciano et al., 2015).

## **Participants**

The participants in this study were female adults, aged 18 or older, who have a biological sister with ASD. The participants were drawn from the southeastern United States. A nonprobability, purposive, convenience sample of four participants was used. Smith and Osborn (2008) stated that for first-time researchers or student researchers, a sample of three participants is best practice.

Research with adults is different than research with children in several important ways (Punch, 2002). For example, a language barrier may exist between child subjects and adult researchers, that is, the adult may ask questions with words or concepts that the child does not understand. Also, rapport development is different between child subjects and adult subjects, as the child may expect to have the adult do the work of building rapport. Adult subjects may be more willing to participate in rapport building, allowing the doors of trust to open more quickly. Finally, analysis of data from adults is different than analysis of data from children. Researchers are adults, and therefore their analysis is based on an adult worldview. Seeing the world from an adult perspective plays out in research in many areas, including researchers being more likely to believe adult subjects and the researcher being more likely to frame the child's responses in adult terms. Punch (2002) stated that adults are less vulnerable to the unequal power distribution found in scientific research. Another factor to consider is research methods oftentimes have to be adapted for children. With adult subjects, the research method can be applied as described by its creator. Finally, concerning validity and reliability, it may be easier for adults to review their own words or work to confirm accuracy (Punch, 2002).

### **Pool of Participants**

I acquired participants for this research project from clinics I am associated with in the Atlanta metropolitan area via posted flyers calling for participants. Subjects who responded to the call for participation were selected for interviews based on their responses on the Participant Demographic Questionnaire (see Appendix C). The Participant Demographic Questionnaire provided the control function necessary in research to ensure the volunteers met basic requirements such as age, gender, and relationship to sister, as well as that they are developmentally appropriate for this study. See Appendix C for the Participant Demographic Questionnaire.

### **Instrumentation**

For this work, I developed a semistructured interview form (see Appendix A). The interview questions are based on the work of Hull et al. (2020), who proposed a female autism phenotype comprising four behaviors or characteristics: social relationships, special interests, internalizing problems, and presenting as neurotypical, a concept termed *camouflaging* in the literature (Bargiela et al., 2016). Each section of the semistructured interview form begins with a priming question and includes two or three questions about the topic of the section. The goal of the semistructured interview form is to get the subject to tell stories or recall events from their life with their sister who has ASD (Smith & Osborn, 2008). See Appendix A for the semistructured interview form.

### **Audio Recordings**

To allow for validation and enhance reliability, each interview session was audio recorded using Apple's Voice Memos. Smith and Osborn (2008) stated that audio recording of entire sessions is the optimal approach to IPA research; a researcher's attempts to write

everything down during the interview will only interfere with the session. Also, in many qualitative research projects, peer review is an accepted form of validation and audio files with complete transcripts are necessary for peer review. See Appendix B for the audio recording consent form.

### **Research Procedures**

After the study was approved by Liberty University's Institutional Review Board, I produced and delivered to local clinics in the Atlanta metropolitan area flyers requesting volunteers to participate in this study. Participants were screened based on age, gender, and developmental history using the Participant Demographic Questionnaire (see Appendix C). Participants were excluded from this research if they also had a neurodevelopmental disability. Each participant was required to be the biological sister (sharing a biological mother and/or father) of a female with ASD. Additionally, all participants were required to be 18 years of age or older.

After being screened for this research project, subjects were asked to sign the consent form (see Appendix B). Before the interview began, participants were given the opportunity to ask questions about the risks of participating in this research. The form explained that there would be no compensation for participating in this study. Additionally, limits of confidentiality were presented on the consent form, including that the research would not constitute therapy, counseling, or advice giving, that all findings are de-identified before reporting, and that the results of this research will be published following a dissertation defense. Finally, it was explained that participants could withdraw from this study at any time and for any reason.

On the day of the interview, participants logged onto Zoom using a link provided by the researcher. They were reminded of the conditions and limitations of the research, including that

they did not have to participate if they did not wish to. Smith and Osborn (2008) stated that the IPA process requires a flexible data collection instrument such as a semistructured interview form. Therefore, participants were given an outline of the interview form (Appendix A) to provide them comfort and expedite the interview process by ensuring that they would stay on topic. The interviews lasted 60 minutes. After the interview session, participants were asked again if they had any questions about the interview or the process. Interview notes were recorded in writing on the semistructured interview form for later review by the subjects and to aid in the flow of the interview session. Smith and Osborn (2008) stated that care should be taken to distinguish between what the participants report and what the researcher concludes. Therefore, participants were also informed that they would be asked to review the researcher's written results and interpretations to verify their accuracy.

Privacy is very important, not just for business transactions but also with medical and mental health information. Limited access is important to protect health data. Briney (2013), in her blog post "Rule of 3" states that all digital data should be stored in three locations: two on-site locations and one off-site location. For this research, the two on-site locations were two independent external hard drives, locked in a filing cabinet at the clinic from where the interviews were conducted. The one off-site location was a third external hard drive locked in a floor safe in an adjacent city.

### **Locating Myself as a Researcher**

Moustakas (1994) noted in his book on phenomenological research that the researcher has a very personal connection to the topic under investigation. The researcher feels connected to the phenomenon he or she wishes to study, not to know all but to experience something new. For me, this connection began in 2012, when I was finishing my master's degree in professional

counseling at Liberty University. The final requirements for the degree were a practicum and internship. In my search for a practicum site, I found a clinic, Triad EduPsych, that specialized in developmental disorders.

I began work there seeing children, mainly boys, with attention deficit/hyperactivity disorder and Asperger's. In time, I developed an interest in the autism spectrum disorders, including pervasive developmental disorder and autistic disorder, as it was called then. However, I quickly noticed that females were extremely underrepresented at the clinic. In my groups at Triad, there were no girls, and in my individual sessions, the girls seemed to all have anxiety disorders.

As a part of my continuing training, my clinical director introduced me to the Adult Aspie Group. There I met two sisters who both had autistic disorder. They were noticeably different than the adult males in the group. At first, I did not understand their diagnoses. They were socially awkward but not restrictive in their use of language like the males. They also actively surveyed the room, whereas the males either looked at no one or at the group leader exclusively. The older sister was not bashful about her interest in the opposite sex, and the younger sister seemed to have no problems talking about her likes or interests either. After the session, I asked my clinical supervisor about the sisters' diagnoses. We talked about how Asperger's presents differently in females. Specifically, we talked about how females seem to be better at hiding their overt symptoms.

In 2019, I read an article by Baron-Cohen (2002) in which he talked about the extreme male brain. I then found other articles by Hull and colleagues (2017, 2020) about females with ASD camouflaging their symptoms so as to appear neurotypical. This led me to a question: Has what I have been seeing for the last seven years a unique female autism phenotype?

## Data Analysis

Smith and Osborn (2008), in their chapter on conducting research using IPA, stated that the best way and likely the most common way to collect data for an IPA is through semistructured interviews. For this work, I used the semistructured interview form found in Appendix A to gather data. In this research project, I was not the sole collector of data, as participants were encouraged to write down their thoughts and feelings as we progressed through the interview to share with me afterward. The session was also audio recorded for transcription and review to ensure the trustworthiness of the results.

Once the interviews were transcribed, I began the process of analyzing the data. McLeod (2011) presented a three-column diagram to be used for analyzing data. First, he suggested the researcher read and reread the transcripts, notes, and other available data. This transcribed material is placed in the middle column of the diagram. In the first column are the notes the researcher took on the material while reading it. In the third column, the emerging themes are noted. I looked for general themes based on what the participants said. I took the general themes and reviewed it for possible ordering of themes and building superordinate themes.

Using an IPA approach to data analysis, I evaluated the interview transcripts and notes shared by the participants for themes and superordinate themes, looking for how each woman makes sense of her life in relation to having a sister with ASD (Smith & Osborn, 2008). The themes were organized into a narrative based on Hull et al.'s (2020) female autism phenotype.

Finally, member checking was conducted, where the study participants reviewed my interpretation for a correct understanding of their statements and stories. The larger narrative is used to convey the research findings of the IPA study. Specifically, the organized themes and superordinate themes deduced from the data analysis have been organized to tell the participant's

story of having a sister with ASD. Each story was compared to the stories of the other participants. The final narrative is composed of the story of all the participants of their lived experiences of being a woman with a sister who has ASD.

### **Trustworthiness**

With regard to validating the data, Moustakas (1994) relayed the story of Humphrey. Humphrey sent the participants of his study his description of their experiences and asked them to review his work for errors in understanding. In an effort to validate the data, having participants review the work of the researcher provides a level of trustworthiness in the data (McLeod, 2011). This process is called member checking or credibility checking. In this research project, participants were offered a copy of select portions of my descriptions of their experiences and asked to comment on the work in an effort to establish trustworthiness in the research. Each participant was given between two and four pages of the transcript with my notes of the identified themes and things the women said during the interview that were particularly interesting.

To further validate the data, quotations from the transcribed interviews are included in the final narrative. McLeod (2011) suggested that researchers give their readers access to as much of the data as possible. IPA data are the transcripts and notes taken by the participants and the researcher during the semistructured interview. By providing this valuable data, future researchers can evaluate for themselves the accuracy of my interpretations of the data.

Conformability is the concept that data from qualitative research can be trusted because all data were collected in exactly the same way. In this case, using a semistructured interview form provides conformability. Similarly, discussing findings in relation to existing research,

within the context of established theory, provides an additional level of conformability (McLeod, 2011).

Triangulation in qualitative research is the process of using multiple sources of information to reach a conclusion. Specifically, in this research, triangulation was used to establish trustworthiness in the data. Data were collected from the transcripts of the interviews, from any notes or verbal feedback from the participants, and from the notes of the researcher.

### **Chapter Summary**

This chapter has described the research methods and goals for this dissertation. It has included an explanation of how participants were selected, including exclusion criteria. Additionally, this chapter has presented the rationale for the interview format and how results from the interviews were analyzed based on an IPA.

## CHAPTER FOUR: RESULTS

The purpose of this IPA research study was to analyze the experiences of adult females who have a sister with ASD using a female autism phenotype as a theoretical outline to guide question construction and interview sessions. This chapter will present data from four interviews conducted in February of 2021 with women who have a sister with ASD. Pseudonyms are used in place of given names to protect the identity of the interviewees, their sisters, and their relations. Four guiding questions were created based on the female autism phenotype outlined by Hull et al. (2020). These four questions serve to organize this chapter. Other themes that arose during the interviews will be noted. The questions used to organize the superordinate themes were:

1. In what ways does having a sister with ASD affect your relationship with her?
2. What particular interests does your sister with ASD have that are unique to her?
3. Does your sister with ASD have any other mental health diagnosis besides ASD?
4. Does your sister with ASD act differently around others than she does around you, acting as if she does not have ASD?

### Demographic Data

To determine suitability for this study and to ensure a homogeneous sample, each participant was given the Participant Demographic Questionnaire (see Appendix C). This questionnaire was designed by the researcher to ensure that all participants met minimum requirements for this study. The participants were asked for their age and gender to ensure they were 18 years old or older and that they were female. They were asked for information on how they were related to their sister who has ASD (biological mother, biological father, or no biological relationship) to ensure a biological relationship. They were also asked if they had ever been diagnosed with ASD or another developmental disorder. All participants completed the

demographic form, and all provided further demographic data including race, birth order, and sister's original diagnosis and age at diagnosis.

All four women in this study completed an hour-long interview with the researcher. They each had a sister who, at the time of diagnosis, was diagnosed with Asperger's syndrome. Three of the four women shared both a biological mother and a biological father with their sister who has ASD. The fourth woman shared only a biological father with her sister with ASD. The four interviewees were between the ages of 18 and 35, with a mean age of 26.25 years. They all identified as white and American. Three of the four women were older than their autistic sister. Two of the sisters with ASD were diagnosed in childhood, while the other two were diagnosed as adults. Misdiagnosis was a theme for both sisters who were diagnosed in adulthood. Three of the four women reported having another member of their family who was suspected of having autism or a developmental disorder. Three of the four women reported other mental health diagnoses in their immediate family.

**Table 4.1**

*Participant Demographics*

Participant	Age	Race	Biological relationship	Sister with ASD is	Sister's original diagnosis	Sister's age at diagnosis
P1 "Jessica"	28	White	Father only	Younger	Asperger's syndrome	Child
P2 "Emily"	18	White	Father & mother	Older	Asperger's syndrome	Child
P3 "Hannah"	24	White	Father & mother	Younger	Asperger's syndrome	Adult
P4 "Ashley"	35	White	Father & mother	Younger	Asperger's syndrome	Adult

### **Superordinate Themes**

Each interview was transcribed and analyzed for interesting or significant material and emerging themes, following the model laid out by Smith and Osborn (2008). Emerging themes were grouped into superordinate themes based on Hull et al.'s (2020) female autism phenotype theory. Themes that emerged that did not appropriately fit into Hull's female autism phenotype were further analyzed, and unique superordinate themes were designed for each.

Each superordinate theme was composed of between two to six themes based on the material gathered from the four interviewees. All of the themes from the work were supported with two or more quotations from the source material. A total of six superordinate themes emerged from the analysis, four of which were based on Hull's female autism phenotype and two that were unique to this work. All six superordinate themes are discussed in detail in Chapter Five of this work. Below is a presentation of the findings of this IPA research in order of the guiding questions followed by a presentation of the additional findings. Pseudonym are used throughout this chapter to protect the identity of the subjects of this research study, their sisters with ASD, and their acquaintances.

**Table 4.2***Superordinate Themes by Guiding Questions*

Guiding question/theme	Superordinate theme
<u>Social relationships</u> : In what ways does having a sister with ASD affect your relationship with her?	Few or no relationships outside of the family One friend in childhood Sister is best with children, strangers, or professionals Isolated
<u>Interests</u> : What particular interests does your sister with autism have that are unique to her?	Different interests from sister Shared interests with sister
<u>Internalizing problems</u> : Does your sister with ASD have any other mental health diagnosis besides ASD?	Diagnosis Suspected diagnosis Tantrums Poor problem-solving skills
<u>Camouflaging</u> : Does your sister with ASD act differently around others than she does around you, acting as if she does not have ASD?	Camouflaging Camouflaging was fatiguing Wanting to look normal Using media to sound normal
<u>Neurotypical sister's interaction with ASD</u>	Did her own research into ASD Sister's relationship served to make her who she is today. Having to exercise self-control to avoid conflict with sister. Used as an outlet for sister's stress Pulling away from sister for psychological protection
<u>Autism and the family</u>	Sister's ASD took precedence over other children's needs Family mental health Noticing that their family was different while growing up

**Overview of the Investigation**

While each woman's meaning-making about having a sister with ASD was unique, there were certain themes in their lives that were similar enough to allow for organization and categorization. These common themes were grouped into six superordinate themes as a means to understanding the lived experiences of these women.

Each woman talked about her relationship with her sister in terms of then and now. They shared how difficult the relationship with their sister who has ASD was growing up. They shared perspectives on extra-familial relationships, namely that their sister had one friend growing up that they are not close to anymore. These women talked about how their sisters continue to function well enough with nonfamily members but struggle with the challenges of adulthood or isolation within their private world.

Many of the women interviewed talked about shared interests with their sister, either in the present or past. They all reported that their sister has her own set of special interests, both academic and pedestrian. Electronic entertainment was reported to be an interest of their sister's by all four of the women.

Internalizing problems, both clinical and social, were reported by all four women. Each woman reported that her sister has symptoms of other disorders and had severe tantrums in the past. Three of the four women reported that someone else in their immediate family also has symptoms of autism or another developmental disorder.

All four participants reported camouflaging behaviors in their sisters. They reported extensive camouflaging at school and church, which they described as fatiguing. They reported the presence of tantrums after their sister had practiced camouflaging for an extended period of time. The women reported that the camouflaging behaviors were overt attempts by their sisters to appear neurotypical and included how they dressed and the use of makeup or the fashioning of their hair.

Three of the four women reported doing their own research into ASD. Additionally, each reported that her sister shaped her thinking about herself and the world, making her who she is today. They each reported being used by her sister as an outlet for stress and having to exercise

self-control to avoid upsetting their sister. As Hannah said, “I tend to try to avoid conflict in general and especially with her. It feels like walking on eggshells a lot.” Jessica stated, “It would be like, oh, don’t have a full reaction, because you don’t want to trigger [her] into a tantrum.”

Finally, all of the women interviewed reported feeling that their sister’s issues took precedence over their own. Family mental health was a major issue for three of the four women, noting that someone in their immediate family had autism-like symptoms or a developmental disorder.

### **Social Relationships**

The participants were asked what their relationship was like with their sister who has ASD. This question produced a number of responses including the theme of the sister’s one friend or very small group of friends. Jessica talked about her sister having one friend in childhood and that they are not friends anymore:

So, I remember, there was one girl; they were friends up unto like my parents moved to Georgia from Florida. They grew up, they met in like a special ed class when they were little. So, they grew up together and then they went to separate high schools and kinda grew apart. But she, her name was Mary; she was like solid, like best friend, always at the house. Um. Then I think as Amanda got older, she was a little less social or like kept a really small group of friends. Um, and it would always be like she would talk about people and stuff, but there was less people coming like over to house or having big group things going on than like I would.

Similarly, Hannah talked about her sister have only one friendship from childhood and that they are not friends anymore either:

I can only think of one [friendship], um, and that would be her friend from elementary school, but. So, they've been friends from elementary to early college, but now my sister is in like the last, last year of college, I think. And, they're not friends anymore; they're not connected or anything like that. Um, but that's the longest one I can think of. So.

She's had friendships, you know, but they [have] always kinda come and gone.

Emily talked about her sister's friendships and the struggle her sister has to make healthy friendships. She, like Jessica, pointed out that her sister's relationships have not lasted:

So, my sister has difficulty making friendships that are healthy. She—I know there's one questions that says, "Does she have any long-term relationship?" For the most part, they really, they have not lasted, and I've always tried to pluck her out of them. Mainly because they have been really bad influences on her. And, that was kinda the biggest problem for her in college and high school. Her problems were not really, um, how she interacted. From my perspective, more of just the people she chose to be with.

Ashley talked about how shallow her sister's friendships were. She reported that her sister had a couple of friends at the lunch table but that they were in conflict at times:

I don't think she had a lot of friends. You sort of have the visual and enough social niceties that you're not running afoul of any authority figures or somebody that might actually do something. But, are you connecting? No. I remember that she had one or two lunch friends that she mentioned at one stage. And I think they may have been more frenemies than friends in the bosom sense.

Similarly, Emily talked about her sister having friends with whom she was in conflict with:

The bullying she actually experienced was actually from her own friends, in the marching band. So, it wasn't like the whole school was out to get her. It was the one club she joined that was out to get her.

Another common theme from the interviews was the sister's interactions with strangers. Three of the four interviewees reported that their sisters did particularly well with nonfamily members such as children, employers, or family friends. Ashley talked about how well her sister got along with teachers and authority figures in school:

Specifically, I remember, she was doing her music recitals, you, I would go to the recitals and it was like a different person was there. You know, ah, relatively happy. Ah, I don't think the—the school administrators thought she was bookish. But they also could see that she was really picking up and remember[ing] what they were doing. So, they were kinda like simultaneous, you know. Teachers like it when people remember what they are teaching about.

Hannah talked about how well her sister gets along with her current employer at college: Right now, I think she has a pretty good relationship with her work-study boss. Um, she worked a few jobs in high school and hated them. But she's always given off like the impression of someone who is very put-together, very detail oriented and, um, employers have tended to like that about her. She's never really, um, she's not one to instigate conflicts or anything like that in public.

Emily talked about her sister working with children and how her employers or the children's parents would not recognize autism in her sister until it was reported to them:

Our bosses would not be able to tell that she had Asperger's. Um, they, I mean they knew. Our bosses were super cool. We had really good bosses. Um, they knew about it

and it was actually helpful for when we had parents who had children with Asperger's in the classroom because we could be like, "Hey, my sister here, she has Asperger's, so she understands completely. I live with her, so I understand completely. Don't worry about your child." So, um [laughing]. So, 'cause there was one child in particular, in our class, the mother was, was drawn to my sister because she had the same diagnosis.

Thirdly, a theme of isolation appeared in the interviews. A majority of the women interviewed reported that their sisters either had been or are currently isolated from others or the outside world. Jessica shared that she feels that her sister with ASD might currently be isolated:

I feel she might be isolated because she doesn't have as much going on. You know, she lives at home and doesn't like really work all the time. Like in her own corner. So, I am trying to reach out and keep in touch. And when I'm home. When I'm home, I'm following her around, like whatcha doing, like, you know to know her as an adult.

Hannah reported that her sister's television viewing caused many problems in the home, including tantrums. Her sister would not want to go out with friends or go to church. Her television viewing habits led to isolation: "It caused her to isolate, and she was very hyper-focused on it, and so she didn't engage with us a lot of the time. It was always a good day when we could watch TV together [laughing]."

Ashley reported that in adulthood, her sister had become isolated. She struggled in high school and college, and when the stress of life was too much for her, her sister returned home and isolated herself from the world:

Unfortunately, after college she never really got her bearings. She is house bound with my parents. Um, I would say post-college, after this incident where she just couldn't

make it on her own, it's like she's just in the house as a shut-in, um, and not very functional.

## **Interests**

The participants were asked what particular interests does your sister with ASD have that are unique to her. In regard to interests, two themes dominated the four interviews: interests unique to the sister with ASD and shared interests between the sisters. Regarding shared interests, Jessica spoke of making it a point to be involved in her sister's interests:

She was super into like literature and art and stuff like that, and I always tried to make it a point to be like interested in what she was creating. Like, I have a framed picture I have had for like almost 10 years now, um, that she drew, and I have it tattooed on me now [laughing].

Emily spoke in her interview about how when she and her sister are together, they engage in shared interests:

We're definitely much better relationship wise in terms of we talk every day, she wants to hang out, we go get smoothies, or we have a dog we like to play with him together. We have a show we watch together, now, whenever we're back at the house. So, we're on good terms now.

Hannah talked specifically about watching TV together. She shared that she and her sister would find shows to watch and get hooked on certain shows together:

We would get hooked on a Netflix show and just sit together and watch it for hours. Um, so that was our thing, and that was her thing as well. She didn't always want to watch TV with me. Sometimes she just needed to just sit there with herself and some TV show. But,

whenever we were sharing a TV show together, it was awesome. Those are some good memories.

Hannah went on to talk about how they worked together to find these television shows to watch:

Oh gosh. Well, we would find them on like the early streaming services, too, so. And then we would find . . . some of them illegally, probably. Um, we watched *Dr. Who* a lot. We loved that one. Um, she does not like that show anymore; she moved on. Um, [laughing] yeah, that's okay. We watched *Avatar: The Last Airbender*. That was a cartoon. I think Nickelodeon would occasionally stream things on their website, and that is where we would watch that.

Ashley talked about having only one interest in common with her sister. Though they played together, she admits that they did not do that very effectively, but both liked to read. She said, "Interest were a weird one for her. She read a lot. So, bookworm-ish. And I suppose in that regard we were somewhat similar."

The interviewees were also keenly aware of their sisters' special interests. All four women talked about special interests that were uniquely their sister's and special interests that caused problems. Emily listed a number of special interests her sister formerly had and currently has:

The main one that's kinda been her special interest, long-term, is history. She's a history major. She's going to grad school [for history]. . . .History is her thing. And, I know that's a typical one, but one that's happening recently is soap making. She makes soap now. She actually started a nonprofit. For, um, for you know, all her profits go to Project Rescue, which is an organization to help girls put into sex trafficking. She's doing really

great with that. She's made a lot of sales. And, it's a really great excuse for her to make soap, all the time. She makes lots of soap. So, in the past, I know music was a big thing. She used to write songs all the time and have me do little music videos with her, but making the videos were not her thing as much, so they did not turn out super awesome, but the idea was nice. She just liked to write all the time. And like I said, art, just kinda on and on. Just like little moments of, "This is my thing; I'm going to learn." And then it passes.

Hannah talked about her sister's special interest causing problems in the family. She shared that her sister's fixation on television led to other issues, including emotional outbursts: I would say that TV was one of those [special interest]. She would often, like, sit in a chair by herself and watch something. And, if anyone were to ask her to do anything during that time, a household chore, work out on the farm, it always started a huge tantrum. Um, lots of screaming and fighting. So, um, that was a big interest for her. Um, she really did not have a lot of hobbies when she was a teenager. I know that when she was younger, she was really obsessed with those melting beads, that you put on the little pegs and then take you ironing board [motioning with her hands], or whatever. She loved those when she was really little. But she didn't have a lot of hobbies or interests beyond television as she started getting older.

Ashley talked about how her sister's special interest created success for her in childhood. However, over the decades, her sister's special academic interests have faded, and now she struggles cognitively:

[Sister's special interest] came out a little more when she went to public school. She took violin. She also was also very good at language in middle school/high school. She was

actually third in the state in German at that time. So, she is very, very good at memorizing large numbers of facts and uh, uh, a fantastic memory. Almost painfully, ah, good. Ah, so those were two interests that she sort of had in high school. But she's kinda gone back to more of how I remember her when she was younger, now. Where there was, really, I couldn't tell you what she was doing. It's . . . like just a distinct inability to process information where you think that they're processing something, and they just don't.

Special interests are considered part of the diagnostic underpinning of ASD, specifically, restricted or repetitive patterns of behavior or interests and insistence on sameness. Women in this study presented with socially acceptable restricted or repetitive patterns of behavior, and their insistence on sameness was often only a problem in the home setting. Examples of these behaviors were academic interests including reading, history, and foreign languages and socially accepted interests such as TV, soap making, and beadwork.

### **Internalizing Problems**

Participants were asked does your sister with ASD have any other mental health diagnosis besides ASD. All four participants reported their sisters had an additional diagnosis or had received treatment for issues such as depression, anxiety, or anorexia nervosa, as well as intellectual impairment.

Jessica, when asked if her sister has other diagnoses, reported that her sister had a history of depression, and she reported on an incident that she perceived as a depressive episode:

I'm not 100% sure, if she has another diagnosis. Um, I know that—I don't know if she is still on them—but I know at one point she was on antidepressants, so I'm assuming she had a depression diagnosis. That was when she was older, and I think they were already

living in Georgia by then. I was in college. . . . I didn't see an effect from that. There was one time she called me hysterically crying because she, I don't remember the exact situation, but it was to the point that it freaked me out and like, okay, what's going to happen? Like I had to call my parents and make sure they, she was home or whatever. So I think that was the effect of a depressive episode or something.

Emily reported that her sister currently has and previously had several disorders including anxiety, depression, and an eating disorder:

She has anxiety for sure. Um, what I wrote down on my notes is she's very easily anxious. So, um, whenever something big happens that needs to be told, now it's kinda been told to me first, and then whenever it kinda has dissipated to where it isn't headline news, we have just a little more information then we can let her know, because unless she knows the other facts, she immediately spirals to the worst possible case. She just assumes a horrible thing; the worst possible thing in her mind is going to happen. Um, in high school, she was most likely depressed, and she had an eating disorder in her first year of college and possibly high school as well.

Hannah shared that her sister has an eating disorder, anxiety, and depression:

She's been going to the gym more, but I don't think that's a hobby; I think that's just something she does. She tries to be healthy. She has an eating disorder. Yeah, I'm jumping way down to the bottom of the questionnaire, but she has depression, anxiety, and an eating disorder, all in one. Um, she's working with a nutritionist and that has been tremendously helpful. She's eating food now.

Additionally, Hannah described a suicide threat after one family counseling session where ASD was the sole topic:

She was obviously very resistant, angry, hateful. Um, and it [counseling session] just wasn't going well. We got out of that meeting. The counselor was kinda dismissive of what I was saying. We got out of that meeting. We came home. She was threatening to kill herself. She was screaming. She was trying to get in her car and drive away.

Ashley talked about her sister being isolated and having difficulty processing information. She described her impression from her observations that ASD is a language issue:, stating that her sister has

just a distinct inability to process information, where you think that they're processing something, and they just don't. Ah, and I found this frequently in the past 10 years, where when I do visit with them, I tell them what's going on with me, and six months later, it's like the conversation didn't happen. And, it will be about very significant and important stuff.

You know, I think the most difficult thing that I've thought about a lot is just the difference . . . [in] language. It makes you think a lot about language because they have it, yet it doesn't mean or signify the thing that it should. And then there's the language normal people are trying to use to cope with the abnormality of the situation. I mean, do we have this autism label? Actually, when my sister was diagnosed, it was "Asperger's." She was diagnosed with Asperger's. You sort of get a label slapped on you, and then it like "Okay, well here's your, here's your dictionary definition," and now what? And I'm grateful for it in a way. It's better than not knowing what's going on. It's vastly better than that. But, . . . where do you go from there? I think you're trying to, people doing what you're doing are trying to answer that question. There isn't a good answer for that question, and, and the language situation is difficult. . . . In fact, so much about autism

feels like it's entirely about language at some level. Um, it's easier for people to understand it when they don't have language. It's very hard for people to understand it there when language is present.

These discussions of co-occurring diagnoses led the participants into a dialogue about problem solving. Each of the women talked about her sister having poor problem-solving skills. Jessica shared a story about her sister calling her for help even though more appropriate options were available:

There were still instances where she would call me, knowing I was nowhere nearby. And be like, "Um, I'm having a problem." Freaking out. Like she called me one day, "Mom's not answering her phone. I need her to pick me up." [laughing] Like, Amanda, I'm in Nebraska. I can't do anything about it.

Hannah talked about her sister not handling responsibility well and instead turning to self-loathing and self-hatred:

She would never just like put herself in her room on her own. She tended to engage in this weird kind of self-loathing power struggle with my mom. Um, she would get upset about something. Um, let's say someone asked her to do the farm chores with dad. She wouldn't want to do that, so she would start resisting that with her language. And, then there would be this shift that happens where she started talking about how she hated herself; she's ugly; I'm terrible. And that gutted my parents, you know, because they loved her so much. And they would try to encourage. It would be this hour-long—not hour, probably hours-long—of just trying to talk her down because she would go from, "I don't want to do my farm chores" to "I hate myself and everything about me" in like the blink of an eye.

Ashley shared her own story of when her sister quit going to classes, made all Fs, and failed out of college because of her inability to problem-solve:

She was a bookworm and kinda coped—masked, if you will—and had good grades but didn't actually, um, she wasn't really able to manage herself, which came out when she went to college. She went to the dorm and it all came unglued. Uh, she secretly quit going to classes in college and got Fs one semester. Straight Fs. Didn't tell anyone. My family didn't realize until the reports came back.

Additionally, three of the four participants reported that their sister would engage in tantrums when frustrated. Jessica described her sister's tantrums: “[She] can very typical seeming all of the time but, you know, once a month or something, throw a crazy tantrum.”

Hannah shared that her sister would save her emotional outbursts for home:

She's never really, um, she's not one to instigate conflicts or anything like that in public. Everything she did, she would save for me and my parents. So, all of those behaviors and tantrums, it all came home; it did not go out in public.

Ashley talked about tantrums that followed her sister having conflict online:

I remember she did some creepy autistic ranting on Facebook as this was occurring [being dismissed from college], which is a new, new phenomena. They kinda had to take her off that. And then, how do we get this person? She went from being seemingly sort of like masking stable to very unstable for maybe a period of two years. Uh, temper tantrums and um, I mean, you know the weird behaviors they do.

For all four of the interviewees, tantrums were a common occurrence when either there was a change in their sister's immediate environment or after she had to present as neurotypical for any period of time.

Finally, of special note, two of the women reported that their sisters were diagnosed with ASD in adulthood. Both of these women reported misdiagnosis for their sister in childhood.

Hannah reported a history of assessment that missed the ASD diagnosis:

Because all of this just blew up at once, I was like, I was really concerned about autism. Like it's, it came to my mind. I had known they had taken her when she was really little to get evaluated, but her counselor, therapist said, "Oh, no. She's not on the spectrum. Her eye contact is way too good." So, um, I had known about that and kept that in the back of my mind for years. When all of these things came up, I was like, this isn't, this isn't quite right, this isn't my sister.

Ashley described her sister being diagnosed as an adult and the certainty that came with the diagnosis. She reported how much of a problem her sister's condition was for the family and how much of a relief it was to finally get a diagnosis:

There was sort of this intervention moment. That's when the diagnosis occurred. . . . I'm the older sister by two years. Um, so I found out just as I was leaving home, actually, that this is the answer. It was like, you know, I'm reading it going, "This is my life. Oh, my God, finally answers." In a way it was, um, so, what was it like growing up? Confusing. You know. Temper tantrums and personal problems that nobody can explain. And, people blamed us and my family.

### **Camouflaging**

The participants were asked, does your sister with ASD act differently around others than she does around you, acting as if she does not have ASD. All four participants reported observing camouflaging behaviors in their sisters. Camouflaging was defined as acting in a

purposeful way or restricting actions or behaviors so as to appear neurotypical. Jessica reported camouflaging behaviors in her sister when friends would come over:

I would always tell new friends and stuff if they were coming over or if we were going to hang out with my family. Like, “Hey, just so you know, my little sister is autistic. She comes across very like normal. You might just think she is socially awkward. But just in case anything happens [laughing] that’s why.”

Emily shared camouflaging behaviors she had observed in her sister that frustrated her and camouflaging she had observed in school:

One of the questions about acting normal, this is the biggest pet peeve of mine, was how she could act so sweet, overly nice to everybody around us. The moment there was anybody outside the family, she became the nicest person on the planet. And, I never met that person before. She’s telling stories that never happened or were based off of a very small story she had expanded into something bigger.

So, in high school you couldn’t tell. No one could ever tell she has Asperger’s. I think, I know, from what I can tell, at least in females, it’s much more easily disguised. It’s just introverted and a little quirky. Um, so she definitely kind of put on the persona, um, in high school where she just stayed quiet. And um, she had her little quirks; she talked about history every once in a while. But she wasn’t, like, completely weird.

Ashley reported her observations of her sister in high school and at music recitals and the “masking” behaviors she engaged in there:

I remember noticing it when she went to public school in the 90s. She was like meticulously imitating the appearance of her cohort. Ah, you know, the hair and so forth. Ah, and she masked, she masked really well. She had me convinced, I think, at times.

Um, so specifically, I remember, she was doing her music recitals. . . . I would go to the recitals and it was like a different person was there.

Hannah reported that she noticed camouflaging behaviors in her sister but did not identify them as a unique symptom until she saw her sister interacting with her husband. When asked, “Does she act differently around others than she does around you?” Hannah shared her experiences:

Oh yea. Oh, absolutely! [laughing]. And I, I kind of like, I knew this growing up, but I didn’t know it until like I got married. My husband became a type of buffer between my sister and I because she wouldn’t fully present those behaviors in front of him. As time went on and once she moved in with us, he became more normal; he became actually more part of the family. So, it was like all of a sudden, that buffer was gone. Um, so I got like a before-and-after picture of what it’s like to be with my sister around other people and to be with my sister as she is. Um, yeah, and it was very different. She’s more, um, more put together. She tries to pull her, like her logical side a little bit more. She definitely tried to engage with . . . social things. I think one of the things she did, looking at number 3, to try and look normal and try and sound normal, she would watch like a lot of social media videos: TikTok, Vines. Um, things that were really popular among people her age. And like, quote those clips from different videos. Um, yea, and that was kinda her way of joking with people in public. She did that a lot around my husband. She just randomly quoted a TikTok, and we would be like, “We don’t watch TikTok.”

The participants reported their sisters engaged in extensive camouflaging at school and church, which was fatiguing. The interviewees explained that tantrums would occur after their sister had practiced camouflaging for an extended period of time. They reported that the camouflaging

behaviors were overt attempts by their sisters to appear neurotypical and included how they dressed and the use of makeup or the fashioning of their hair.

### **Interviewees' Interactions with ASD**

In the interviews, additional, unprompted themes arose, including the interviewees' interactions with ASD and the families' interactions with ASD. The theme of doing their own research into ASD spontaneously appeared in a majority of the interviews. Jessica shared that her own research even led to her doing projects on ASD in school:

I tried to make it a point to research autism, and like, be involved in things. And my family, we would like do Autism Speaks, which I know is weird now, but we would do things with them every year. And, um, I remember I did, like, projects on autism throughout school. And, I feel like, . . . I wanted to be closer to her because of it.

Emily reported that she learned about ASD because of her interactions with her sister and her friends with ASD. This effort to understand ASD led to her becoming a spokesperson for ASD to those around her:

And then I learned a lot about autism on my own. My mom has been kinda the biggest resource, mainly because she has studied it all her life. So, you know, if I have a question, I direct it to her first. But, if there was ever anything else, I was curious about, you know, I Googled it. And I've kinda become a weird spokesperson for Asperger's, to people who are like, "Oh, what is that? Oh, my friend, my sister has Asperger's. I've heard of that. That's on the spectrum. What does that really mean?"

Hannah reported that after her sister's eating disorder came to light, she began doing her own research into ASD, which her sister was previously assessed for and determined not to have:

When all of these things came up, I was like, this isn't, this isn't quite right; this isn't my sister. But it just didn't sit well. So, I started doing a little research, communicating with Stephanie Holmes [counselor and autism specialist] and asking some questions. And then I opened up a conversation with my parents and I was like, "We might need to get her evaluated."

Another theme that spontaneously appeared during the interviews was that having a sister with ASD significantly shaped who the interviewees are today. All four women reported specific and significant impacts on their lives because of their sisters with ASD. Ashley shared her insights from having a sister with ASD:

Of course, this is one of the chief questions I've spent a lot of time, uh, thinking about. . . . Where to start with that, what would be the most important thing? Well, I do think that uh, having that background, certainly I have a different perspective on the world. You have to sorta accept on a deep level that not everybody is processing the world the same way. I think that's like an insight into life that a lot of people just never have the need to, to face. I know a lot of people who genuinely believe, "I see the world this way and everyone else has to see the world this way." They're having the same feeling; they're projecting their own internal processing, feelings onto other people. They assume it's like that. You know I had to grapple pretty heavily with the fact that, no, actually that some people are processing the world very differently and sometimes that's, you know, becomes a clinical problem. . . . I think it's impacted on a philosophical level.

By comparison, Hannah reported that having a sister with ASD has driven her to want to help other families with autistic family members:

I'm in school to become a counselor at this point, um, not only because of the impact of my sister's mental health issues on herself, but because of the impact it had on all of us. So, I've just continued to feel kind of burdened for family members of people on the spectrum, because . . . sometimes you just don't know what to do. And also, currently I'm an ABA [applied behavior analysis] therapist so I work with children on the spectrum. Um, most of the kids I work with are very different from my sister, you know; they're nonverbal. Um, things like that. But, um, I would not have considered that job had it not been for my relationship with my sister. And, that job has led me to realize, wow, parents need support. Siblings need support. Um, so that's kinda why I'm going into counseling. Emily talked about how having a sister with ASD has made her a better person. Growing up with her autistic sister has shaped the way she treats others:

I definitely think with my relationship with her, while it was hard at times, I've learned a lot about maybe giving grace to people. You know, um, like I said in high school, for some reason, all my friends were on the spectrum; I don't know why. I didn't go actively thinking, "I'm going to find myself a friend with Asperger's." I didn't, I didn't look for that. That was not my goal. But, . . . I guess it was just how I interacted with those people. You know, drew them towards me, and I understood how to communicate with them because I had so much practice at home. And then there's just kinda grace for anybody on the spectrum.

Jessica summarized how her sister with ASD has shaped her, making her who she is today. She talked about being more understanding, realizing things are not always what they appear, and she talked about her own feelings about ASD:

First of all, I can spot autism from a mile away [laughing]. There are some people I have interacted with that I'm like, okay, they have to be on the spectrum; they absolutely have to be, because some of the same behaviors I see in them, I'm like this is Amanda absolutely. Like this is it. So, that's kinda cool. But [laughing] I feel like but also, it's made me kind of know, as I grow up, like, not everything is what it seems. Amanda can very typical-seeming all of the time but, you know, once a month or something, throw a crazy tantrum. So, you don't really know what's going on with someone. Um, it's also been a huge thing of mine for most of my life to treat everyone with respect and dignity because they deserve that. Um, yeah, I feel like it's just made me more understanding and just a little more caring towards people. Because you really don't know, and like I've heard people make fun of her before, and that sucks, so I'm not going to do that to someone. But I, like, volunteered with a lot of special needs things as I got older.

Another theme that appeared during the interviews, unprompted, was the theme of being used by the sister with ASD as an outlet for her stress. All four participants reported that their sister had, in the past, physically used them to manage or relieve their frustrations. Jessica talked about her sister, even as a young child, being physically inappropriate when frustrated:

Sometimes I feel it was very typical for siblings, 'cause even my older sisters and my brother, we would have kinda conflict every now and then, but I'll never forget one time, I was probably like seven or like eight, and we have a pool in our backyard. And, I remember my mom being like, don't let Amanda in the pool yet. Because she was inside, and she was like, "Wait until I come out." So, I was, like, standing by the pool waiting, guarding it. And, she went over and bit my leg [laughing]. And, like ah, and like bit me,

and that is like one thing, I'm like, "Girl [laughing]. You tried to take a chunk out of my leg."

Emily talked about being struck by her sister out of frustration. She shared that her sister was frustrated after she had compared her own work to that of the interviewee's:

She and I are both very artsy. . . . When we were younger, that was a problem because her art didn't always look how my art looked. . . . The story that comes to mind is that she and I were making cards for our parent's birthday. And, she thought that mine looked better. And, I was a brat and said, "Ha ha, mine looks better." And, we were working on a little plastic kid table and she hit me with it. And [laughing] she has not hurt me since then, by the way, because my mom scared the living daylights out of her just chasing her into her room. [laughing]

Participants 3 and 4 talked about their sisters' emotional side and being used by them as outlets for their sisters' stress. Specifically, Hannah shared that her sister would never lash out emotionally in public but would save her overflow of emotion for her at home:

She's never really, um, she's not one to instigate conflicts or anything like that in public. Everything she did, she would save for me and my parents. So, all of those behaviors and tantrums, it all came home; it did not go out in public. So, I would say though, . . . we were in youth group together at our church, and everybody was always super intimidated by my sister because she had a very angry face, um, and she would always put off this front, like, "Don't come near me. How dare you talk to me?" kind of thing. Um, and then she would come home confused. "Why would nobody talk to me at youth group tonight?" "Why does everyone think I'm so mean?"

Similarly, Ashley shared that her sister would take the stress from social performance out on her, while at other times, the emotional outbursts would seemingly come from nowhere but still be directed toward her:

I remember after these recitals, we would come home, and she would almost, you, you would barely make it to the car even. Then she would start breaking down in tears and anger. There would be some kind of blowup. I don't even remember about what. I don't think it was about anything. Like, there would be this facial expression; it's like that Jekyll and Hyde moment occurs. . . . Quite frankly, a lot of it got taken out on me. You know, like, um, you would be sitting there. You would be doing absolutely nothing; you made a sound. Very sound sensitive, and the next thing you know there's this, you know, bizarre, meltdown-ish behavior occurring, which sometimes is blamed on you. Somehow just being alive. [laughing]

Another theme that appeared during the interviews was that of the interviewee pulling away from her sister or distancing herself from her sister with ASD. While most of the participants stated that they did this for their own psychological health, all reported on the benefits of having purposefully created this time apart in adulthood. Ashley talked about avoiding negativity by maintaining a safe distance from her sister and family:

I see the family maybe once every couple of months. We live in town; they're here in town, Atlanta. . . . Its, ah, strained, deliberately strained. I, uh, I'm respectful of them, and I want to help them, but they're kinda stuck in this situation that they don't know how to get out of, and I ended up realizing that they kind of like pull you into their world. And I grew up in that world, but I don't want to continue inhabiting that kind of negativity when I don't have to necessarily. So, I keep a certain amount of distance from it. We see

each you. You know how they are about certain events. So, for birthdays and holidays, if I don't see them, they get pretty upset. And I don't want them to feel badly, I just can't—don't care to have a really close relationship. So, we see each other for holidays and stuff like that. It's very brief, simple a couple of hours.

She continued,

To some extent, I've coped by putting some distance between myself, and, . . . like I've said, family contact is deliberately limited. Just because I find when I'm around them, they suck me back into that place, and I suck myself back into that place. So, I try to spend as much time as I can with people who don't—where there's not that background, so I can soak in different behaviors.

Hannah talked about emotionally separating herself from her sister due to the pain of coping with her sister's emotional inconsistencies:

I feel like in a lot of ways, it shut me down. Um, in response to her severe outbursts, I would always stuff my own emotions. Um, and any time, let's say, I had a conflict in high school that was really emotional for me, if I were to bring that up with my parents, maybe 10 minutes into the conversation, my sister would be upset about something and she would take the conversation away, and suddenly it would be, "I hate myself" all over again. So, that lead me to kinda separating my emotional life from my sister. Um, even today, I have a really hard time sharing with her, even through text message, um, because if there is anything going on with me, there's something worse going on with her just all the time. Um, so I'm definitely more emotionally separate from my sister than others.

Emily talked about an early life experience that led her to pull away from her sister with ASD to protect herself emotionally:

When I was in middle school/elementary school, she was working at junior high/high school area. And, I, I don't even have a complete memory here. But I, when I felt like I need to shut myself off from my sister relationship because it wasn't healthy, personally, was when I tried to go into her room, and she shut the door really fast and said, "Get out. I don't want to be your sister. I hate you." I had done nothing. She had a bad day and took it out on me. And, I was like, "I don't know what I did, but I don't want to go to her room ever again." Like, even if she invites me, I'm going to be cautious because I don't want to deal with that.

Jessica shared that when her family moved for the last time, she took the opportunity as an adult to go and experience the world. She pulled away from her sister with ASD and her parents:

When my parents moved . . . to Georgia, I stayed in Florida and dropped out of college and stuff. And I started traveling. I worked in national parks for two summers, and it was super cool. But my boyfriend, who I live with now, he's from Nebraska and I met him working at the Grand Canyon. So, kinda just like, ha, I haven't lived near my family or [been] super attached anymore. Like there are some people who are like, "I have to see my family every year, four times a year." And we're kinda not like that. A couple of times is fine [laughing]. So, I was, I felt like, I can leave and move and travel and have my own life now, and not be worried about them.

Finally, three of the four participants talked about having to exercise self-control to avoid upsetting their sister with ASD. This felt obligation led to resentment. When asked if she felt that her sister's ASD diagnosis took precedence over her own issues, Jessica shared about having to restrain herself when her sister became upset:

Sometimes it was like, if we had a normal or, like, you know, a typical sibling quarrel or something, like, I used the bathroom too long, or you know something typical, it would be like, “Oh, don’t have a full reaction, because you don’t want to trigger Amanda into a tantrum,” or, like, you know, “She’s different, so be—tip-toe around it instead of like feel your feelings,” you know. And then, like, as I got older and started having different issues and stuff, I felt like, okay, don’t be like another problem. You know, like, I didn’t want to come to my parents and be like, “Hey, I kinda hate my life” [laughing]. At some point, . . . I just kind of dealt with it on my own.

Emily shared a story about accommodating her sister to avoid a blowup. She shared that she is a flexible person but still wishes for understanding from others:

Whenever I went to my grandparent’s house, they would have me sleep on the really awful couch, that same couch they’ve had for 20 years. . . . Even though that couch is still awful and even smaller to you now, you can’t sleep in the same room [with sister]. And, something like that I think about like, if my parents are still her parents, they can be like, “Hey, we know you can have her in your room, but because I don’t want to have to deal with you being mad about it, I’m just going to make her sleep on the couch again.” So, small little subtleties like that bothered me in a way I did not realize until I started thinking about it. I understand why, it’s just not worth the blow up, when I, you know a pretty flexible person, willing to do most things. You know, it’s just, in that little inkling of your mind, it’s just I don’t think that my parents love her more or anything, it’s just more of a, sometimes, it’s like, I wish they would, you know, maybe think about what I want first, once in a while.

Hannah talked about exercising self-control and not allowing herself to have certain emotional experiences around her sister with ASD, believing that those emotions would fuel her sister's anger. However, by not showing emotion, she found that she still upset her sister:

I think I didn't allow myself. Um, I've always been somebody to repress my emotions. Um, and that drove my sister insane. She would try and egg me on and get me to, like, unload on her. She didn't understand why I was, like, not crying a lot. She didn't understand why I was so emotionally distant, I guess. Um, and, I just, I didn't want to bring it up.

### **Autism and the Family**

A sixth superordinate theme appeared in the interviews: autism and the family. The interviewees talked about their experiences with their family and how they were different because their sister had ASD. First, the four women reported that their sisters' ASD took precedence over their needs or wants, with the Ashley even talking about being parentified. Jessica talked about both herself and her brother having problems that they did not want to carry to their parents because they did not feel they would be heard:

As I got older and started having different issues and stuff, I felt like, "Okay, don't be, like, another problem." You know, like, I didn't want to come to my parents and be like "Hey, I kinda hate my life" [laughing]. At some point, . . . I just kind of dealt with it on my own. I'm sure my brother probably felt the same way at some points in his life. He had some difficulties.

Emily talked about noticing when she was younger that her sister with ASD got more attention from their parents than she did. She went on to share that their mother took extra steps to get her sister with ASD to talk to her:

I do think, with parent life, maybe I shared that sometimes it did feel like she did get a little bit more, you know, extra treatment than I always needed. . . . When I was younger, I used the word “neglect” to my parents. They made fun of me, saying that’s not, you’re not neglected. Okay, you know, I did recognize that there was more emphasis on their relationship with her. Something that stands out to me a lot was when my sister was going through a lot in high school, my mom actually paid her to talk to her about what was going on because she needed a reason to tell my mom, and my mom needed to know she was okay because there was obviously something horrible going on.

Hannah explained that when she shared her problems with her parents, her sister with ASD would interrupt and lead the conversation away, and her parents would follow because of how emotional her sister would become:

Any time, let’s say, I had a conflict in high school that was really emotional for me, if I were to bring that up with my parents, maybe 10 minutes into the conversation, my sister would be upset about something, and she would take the conversation away, and suddenly it would be, “I hate myself” all over again. Because there was never enough time to hash out what I was feeling because my sister always needed to do that, so, um, I didn’t feel like there was space for me to experience these things, so I just didn’t experience them.

Ashley talked about being parentified. She shared that though she was the older sibling, she never felt that way:

It was almost like being an only child in a way, I would say, maybe. Only worse in that you have a sibling. . . . Like my parents would ask me, “Could you take care of my sister?” Well, you’re talking about taking care of somebody who threw temper tantrums, .

. . . acts out. . . . She didn't listen to me at all. So, I couldn't have any older sibling role, in that way.

Additionally, the interviewees reported on a family history of mental illness and possible developmental disorders in themselves and others. Two specific subthemes appeared here: mental health issues in the immediate family and developmental disorders in the immediate family. When asked whether her mother had any mental health issues, Ashley responded,

Yea, anxiety for sure. Kind of hypochondria that continued, a lot like you know. Um, dieting. Lots of obsession with various diets over the years. Like, I must have been through this 20 times where it starts off with, you know, "I went to the library and I got a book. And the book says, if we only do X"—it serves some kind of food, usually, diet thing—"but, then, then we won't have problem Y."

Hannah discussed her own experiences with situational anxiety after she married and moved away from home:

I think I've had my moments. Like I've, I've dealt with some anxiety in my life. When I first got married, I started a new job and it was horrible. Um, I was a classroom teacher actually, and I just, it was not for me. So, I've had some anxiety throughout my life but nothing that was pervasive.

Emily talked about her father's diagnosis:

My dad also has Asperger's. Um, he, you wouldn't really tell talking to him. He's more like a silent type kinda of thing. Where he doesn't really open up unless he knows you very well. I don't know; he—you just would not be able to talk to him and tell unless you were in the family and around him long enough.

Jessica shared that she believes, had her brother been tested, he too would be diagnosed with ASD. She reported that she experiences symptoms of anxiety and depression:

I think my brother, who also shares the same dad as me and Amanda, um, I guarantee that if he had been looked at, he would have been on the spectrum, for sure. [laughing] And I, um, know that I deal with a lot of anxiety and depression situations, but I've never been diagnosed either.

Finally, the theme of noticing that their family was different while the interviewees were growing up presented during the interviews. Half of the women interviewed reported that even at an early age, they realized that their family was different because of their sister with ASD.

Jessica talked about having to adjust:

Some of these things I'm like, I can't believe I still remember, but it was so weird to me growing up. To have to adjust to not—just not being the youngest sibling, because she took that when she was born, but also, now, she has a whole different regimen and schedule and all this stuff. So, it was very like a taste of something different when you're younger.

Ashley shared her story of family outings where she realized her family was different because of her sister with ASD:

I remember we would go to socialize in a neighborhood and/or in various situations and there would inevitably be —first it would go well. Then she gets tired and cranky. Then there's some kind of blowup. Dramatic meltdown, and that becomes the center of attention. Right? Now not only her, but your entire family is tired in this troubled situation. And you know, the fellow six-year-olds, they don't —you're six, you're seven, you're eight years old and they see that, and "Wow, that's scary." They wander off. So,

[it was] actually kinda hard, ah, socially. And then at seven and eight and nine years old, you have people asking you questions. 'Cause even at eight years old, an eight- or nine-year-old is going, is kind of like, "What?" [laughing] You know. And what are you going to tell them? I remember not having explanations. . . . I specifically remember having a phase when I was maybe nine, I, I started to get a little older. . . . I had a friend, and I basically said, "My sister, she's a jackass." You know, I would, I started using some language about it. . . . I was both personally frustrated and, on some level, I wanted the people around me to know, hey, I wanted nothing to do with this, I'm not like— [laughing]. I, I find this as miserable as you do.

### **Chapter Summary**

In this chapter, the results from the four interviews of women who have a sister with ASD were presented. The lived experiences of these women produced six superordinate themes including the four characteristics found in Hull's female autism phenotype as well as two spontaneous superordinate themes of the interviewees' interaction with autism and autism and the family. These themes were presented according to the guiding questions, based on the work of Hull et al. (2020), first summarized and then connected directly to each woman's stories.

## **CHAPTER FIVE: DISCUSSION AND CONCLUSION**

This chapter will examine the implications of the findings from this IPA study of women who have a sister with ASD. Interpretations of the interviewees' actual responses will be discussed in terms of the female autism phenotype, outlined by Hull et al. (2020). Conclusions will be drawn by comparing these findings with existing literature. Limitations of this IPA study will be considered. Recommendations for working with families who have a sister with ASD will be discussed. Finally, the researcher's personal experiences of conducting this IPA study will be explored.

### **Interpretations**

The goal of this work is to provide a greater understanding of a female autism phenotype by investigating the lived experiences of women who have a sister with ASD. The hope was that additional insights into ASD in women would be gained from interviews with the sisters of women with ASD. To that end, this chapter will consider the findings of this study in light of current research. Results from the analysis of the interviews' content will be compared to the existing literature and the current understanding of autism in females.

### **Observations of Social Relationships of Sisters with ASD**

Holtmann et al. (2007) noted that females with ASD struggle more with social interactions than their male counterparts. The reports by subjects in this IPA study confirmed a limited range of social interactions for their sisters with ASD. All of the women reported that during social interactions, their sisters would present as neurotypical, a phenomenon that has come to be known as "camouflaging" (Dean et al., 2017, p. 678; Rynkiewicz et al., 2016, p. 2). Though the circumstances vary as to when and where the sister with ASD interacted socially and camouflaged their ASD symptoms, all of the women noted considerable difficulty with social

interactions, even to the point that their sisters would have emotional outbursts and isolate afterward. The conclusion is the camouflaging requires an incredible amount of emotional energy and is not sustainable over an extended period of time.

Regarding their own experiences, all of the subjects in this study noted that their social spheres were restricted because of their sister with ASD, a finding supported by the work of Barak-Levy et al. (2010) and Ward et al. (2016). This finding brings light to an area of need in the lives of family members of women with ASD, specifically the need for social and emotional support. As a family, the women reported, they would engage in social outings like Autism Speaks events, neighborhood parties, and church. However, inevitably, the sister would tire of the crowd, and the family would have to leave the social setting because tantrums would follow their sister's social fatigue. This pattern of behavior led to a restriction in the social interactions of the women in this study. Limiting of social interactions created resentment that many of the participants reported they continue to struggle with.

All four of the subjects stated that they made considerable efforts to connect individually with their sister who has ASD; however, conflict between themselves and their sister persisted. This finding is in line with the work of Kaminsky and Dewey (2001), who found that relationships between neurotypical and autistic siblings was marked by less intimacy, less prosocial behavior, and less nurturance in children age eight to 18. Though the findings of this IPA study cannot be generalized across all sister-sister relationships, it does highlight an important element and possibly a stage that autistic and neurotypical sisters specifically pass through in which the neurotypical sister attempts to make a connection with her autistic sister using approaches that she feels are successful with other neurotypical individuals. However,

when these approaches fail to achieve the desired goals, conflict ensues, and resentment is reinforced.

**Table 5.1**

*Summary of Observations of Social Relationships of Sisters with ASD*

Findings	Interpretation
A limited range of social interactions for their sisters with ASD	Leads to emotional outbursts because camouflaging is tiring for the sister with ASD
Women's social life was limited because of sister with ASD	A restriction in the woman's social life leads to resentment against sister with ASD.
Women's attempts to connect with their sister who has ASD failed	Because their approach is neurotypically based. Its failure leads to conflicts.

**Shared and Different Interests of Women and their Sister with ASD**

Another fascinating finding of this IPA study of women who have a sister with ASD was the participants' shared interests with their sister. Van Wijngaarden-Cremers et al. (2014) found that generally, autistic females present with fewer stereotyped, restricted, and repetitive behaviors than males, which likely aided in the women's ability to share interests. The majority of women in this study reported a desire to be interested in what their sister was interested in for the purposes of connecting emotionally with their sister. Oftentimes, these shared interests were manufactured, meaning that the women would purposely seek interests in digital entertainment or academic subjects to identify with their sister with ASD. The women reported watching television shows, movies, or online series with their sister. Half of the participants reported that these specific shared interests continue even into adulthood, a finding supported by the work of Orsmond et al. (2009). The interviewees' goals of making a meaningful connection with their sisters was facilitated by the specific interest of the sister with ASD. This finding likely points to

an area of skill development needed for neurotypical family members to create and maintain good relationships with women with ASD.

Similarly, the subjects reported disengaging in certain interests or activities after a disagreement, falling out, or boundary violation by the sister with ASD. This corresponds with the work of Cridland et al. (2016), who stated that sisters reported burnout, a lack of appreciation, and criticism when trying to help their sibling with ASD. Two of the respondents reported that their sister engaged in what they thought was a shared activity alone, leaving them feeling betrayed by their sister with ASD. This, in turn, led to a pulling away from that shared activity or interest, along with hurt feelings. All four women reported that their sisters misused or overused a shared activity, leading to a breaking of the relationship. The expected mutual trust and respect of the relationship created a deluge of resentment and conflict when it was violated by the sister with ASD. This pattern of self-seeking reported by the women about their sisters with ASD creates a complex interrelational conflict between the woman and her sister, which led to times of not talking to one another and attempts to physically separate from one another.

### **Table 5.2**

*Summary of Shared and Different Interests of Women and Their Sisters With ASD*

<b>Findings</b>	<b>Interpretation</b>
Women would join with their sister who has ASD, becoming interested in what the sister was interested in	As an attempt to connect emotionally with their sister who has ASD
Women would disengage from these same shared interests when they felt that their sister with ASD had abandoned the cooperative nature of the exercise	Because they felt betrayed by their sister who treated a shared interest or activity as if it were not shared

### **Co-occurring Disorders in Sisters With ASD and the Interviewees' Mental Health**

The subjects provided a wealth of information on co-occurring disorders in their sisters with ASD. Research conducted by Hartley and Sikora (2009) found that females with ASD experienced more anxiety and depression symptoms than males with ASD, and work by Sedgewick et al. (2020) found self-reported symptoms of depression, anxiety, and eating disorders to be most frequent in autistic women. Therefore, the participants were primed with a question about co-occurring disorder that specifically noted depression, anxiety, and eating disorders. It was not expected that the women in this research study would have all of their sisters' medical or mental health information. Instead, the women were asked about co-occurring disorders because they likely knew about major mental health issues in their sisters' lives and were significantly affected by them in some way.

Cassidy et al. (2014, 2018) found that autistic women aged 16 to 74 were more likely than autistic men to have depressive symptoms, experience suicidal ideations, and make suicide attempts. Results from this IPA research support these findings, as as three of the four subjects reported depressive symptoms in their sister with ASD and one relayed a story of a suicide threat by their sister after a counseling session in which ASD was the topic. This sister was diagnosed as an adult, which Fowler and O'Connor (2020) found increases the likelihood of depression and suicidal behaviors. The prevalence of mood disorders co-occurring with ASD is well founded in the literature. The women in this study saw depression in their sisters with ASD as a problem in living and distinct from their ASD diagnoses. Treatment for the co-occurring disorder was reported by the women to be individually focused with only the occasional family involvement. Findings from these interviews suggest that the sisters' mood issues affect the entire family;

therefore, future considerations should include family therapy and parent training in the treatment of depression in women with ASD.

Anxiety co-occurring with ASD was also reported by the participants. Three of the women interviewed reported symptoms of anxiety in their sister with ASD. This finding is consistent with the work of Bargiela et al. (2016), who found that 93% of their own sample of adult women with ASD suffered from an anxiety disorder, and Dworzynski et al. (2012), who found that female children with ASD were more likely to have anxiety than males with ASD. The participants produced some unique accounts of situations caused by their sisters' anxiety. The sister with ASD would engage in inappropriate social interactions which oftentimes would lead to the family avoiding future social engagements. The women interviewed reported that their sisters with ASD experienced anxiety in a variety of social settings, including church and work. The participants' reports of anxiety in their sisters often included aggressive, avoidant behaviors such as tantrums, which forced their parents to remove the sister with ASD from the setting.

Half of the interviewees reported that their sister with ASD had an eating disorder. Råstam (2008) found that abnormal eating behaviors are more common in people with ASD than in neurotypical individuals, and Pooni et al. (2012) found that children and young adults who experienced early-onset eating disorders also tended to have the repetitive and stereotyped behaviors traits of ASD. Though none of the participants reported any specific diagnosis, they each reported that the symptoms were severe enough to cause problems for their sister and to require professional treatment. In both these interviews, the disordered eating was associated with social interaction outside of the family. The participants connected the disordered eating with their sister's desire for acceptance from nonfamily members. Interestingly, the disordered

eating was not assumed to be related to body image, as in anorexia, nor texture avoidance, as in ASD, but was seen as an attempt to maintain the extrafamilial relationship.

Three of the four participants talked about their sister having “tantrums.” Though the concept of a tantrum was not defined in the interviews, the women’s use of synonyms during the interview help define the concept for their own experiences. Jessica talked about a tantrum being something “crazy” and something her sister “threw” once a month or so. Hannah talked about tantrums being “behaviors” and implied that they were conflictual. Ashley defined tantrums as “weird behaviors” and gave examples of “ranting on Facebook” and crying and screaming after a piano recital. This crude method of outlining a concept allows for a fuller understanding of the lived experiences of women who have a sister with ASD, as the definition is based on their own words and ideas. The interviewees all reported that the tantrums their sisters had were behaviors they engaged in almost exclusively around the family. They were disruptive, not prosocial, and required intervention to protect the individual from themselves and social criticism. Tantrums appeared to occur exclusively after a stressful situation and serve as an example of a poor problem-solving skill. These findings are similar to those of Ross and Cuskelly (2006), who reported that 84% of their respondents noted aggression as the most common stressor in the sibling relationship.

During the course of the interviews, all four women reported on their own mental health challenges. In one study done with siblings of individuals with a disability, almost a third of the subjects self-reported emotional or behavior problems (Giallo et al., 2012). The participants in this IPA study reported anxiety, depression, or self-image issues, all undiagnosed. In addition, the women shared that they felt they were unable to bring their emotional difficulties to their parents, believing that their parents would not give them the attention they needed. This theme of

the needs of the sister with ASD taking precedence was found throughout the four interviews. Benderix and Sivberg (2007) found that respondents who assisted in caring for a sibling with ASD would not talk to their parents about their own problems because they did not want to burden their parents with their needs. Though the subjects in this study are not a representative sample of the population, they do highlight a major need in the field of psychotherapy, the need to consider ASD treatment from a family perspective, acknowledging that ASD affects every member of the family.

**Table 5.3**

*Summary Co-occurring Disorders in Sisters With ASD and the Interviewees' Mental Health*

Findings	Interpretation
Depression	The women saw depression in their sisters with ASD as a problem in living and distinct from their ASD diagnosis.
Anxiety	The women understood anxiety as an expected part of ASD in a variety of settings.
Eating disorders	The disordered eating was not assumed to be related to body image nor texture avoidance but as an attempt to maintain an extrafamilial relationship.
Tantrums	The sisters would act out because of feels of stress related to social pressure
Interviewees' mental health	Subjects experienced mental health issues that often went untreated.

### **Camouflaging ASD Symptoms and Acting Differently Around Others**

All four women reported that their sisters with ASD acted differently around others than they did around them. Attempting to mask ASD symptoms by appropriately using nonverbal cues or by hiding social deficits is called camouflaging (Dean et al., 2017; Rynkiewicz et al., 2016). Hull et al. (2020) refer to camouflaging as purposeful attempts to minimize the appearance of autistic traits in social settings. The participants reported that their sisters acted cordially around nonfamily members. Their sisters with ASD were well behaved at church, able

to function at school, and well-mannered around guests in the home. Each woman reported that others could not tell her sister had ASD by listening to them speak, a finding that is consistent with the work of Lawson (2019). Camouflaging is an important trait because it indicates that the women with ASD recognize their autistic presentation as different from others and want to do something about those autistic traits. Camouflaging also highlights the innate desire in women with ASD to connect with others socially, so much so that three of the four women reported that their sister's camouflaging behaviors had them convinced that she was socially competent.

The subjects in this study talked about attempting to bond with their sisters with ASD by doing things for them that they felt would help them fit in socially to help them camouflage. This often involved the sister with ASD getting advice from the interviewee, her peers, and electronic media on how to present as neurotypical. Two of the women stated that they helped their sister with her appearance: clothing choices, hairstyles, or makeup. These women reported that this time was an opportunity for them to bond over shared interests, including their appearance. The participants also talked about their sisters finding inspiration or motivation from their peers. One of the interviewees shared that when her sister went to public school, she became very interested in fashion and fitting in. She started dressing differently and acting differently around the other students they encountered at church and at parties. All four women reported that their sisters learned from electronic media ways to camouflage their autistic behaviors and fit in with peers. The sisters would watch videos on hair styling or makeup and implement what they had learned for school or church. They would mimic social media personalities in their style of talking and relating to others, including trying to be funny. This use of social media to learn to camouflage autistic traits is an area yet to be explored in the research literature but deserves attention.

All of the subjects talked about their sisters' camouflaging behaviors causing conflict. One oft-reported problem was the interviewees feeling angered and frustrated by their sisters' ability to act normal around others but her apparent refusal to do so with them. This behavior by the sister with ASD signaled to the women being interviewed that they were not important enough for their sisters to try to act normal around them. Another example of camouflaging causing conflict was at the intersection of camouflaging and the social environment. The sister with ASD could not maintain the camouflage indefinitely, and in social situations like church, school, or public gatherings, she would "throw a crazy tantrum," as Jessica said, as she became fatigued from presenting as neurotypical. These tantrums would force the family to react immediately, usually by taking the sister with ASD away from the social setting. This again highlights the work of Lai et al. (2011), who reported that camouflaging comes at an incredible cost to the sister with ASD, as it requires sustained mental effort, which inevitably leads to emotional dysregulation. This also highlights an area of value to psychotherapy, helping the woman with ASD find a balance between their social presentation and their personal world.

#### **Table 5.4**

##### *Summary of Camouflaging ASD Symptoms and Acting Differently Around Others*

<u>Findings</u>	<u>Interpretation</u>
Sister's with ASD will camouflage their ASD symptoms.	Because they want to fit in socially and be accepted by peers
Women aided their sister in learning to camouflage their ASD symptoms	Believing that if they gave their sister what she wanted then their sister would give them what they want, namely a sisterly relationship
Camouflaging lead to conflict and hurt feelings in the women who have a sister with ASD	Because women felt unloved by their sister who would not act neurotypical around them but would instead act neurotypical around others until she could not anymore

### **The Participants' Interaction with ASD**

Each subject interviewed talked about her own response to ASD and her personal world. Out of the first interview spontaneously came the question, "In what way has having a sister with ASD made you who you are today?" Because of the richness of data that came from this question, I perpetuated the question into all succeeding interviews. This question produced extremely valuable data from all of the interviewees. All four subjects saw themselves as a product, in part, of their childhood experiences of growing up with a sister who has ASD. Some participants reported having spent years thinking about the effects their sister had on them. They all admitted that their sister has shaped the way they see the world. The interviewees used words like "grace" and "understanding" to describe how they are different because of their sisters with ASD. Jessica said it this way, "I feel like I've become an empathic person because I wanted to be there for Amanda. I wanted to be that empathic person for her." Emily said, "I definitely think with my relationship with her, while it was hard at times, I've learned a lot about maybe giving grace to people." These findings are in line with the work of Ward et al. (2016), whose participants reported a host of positive experiences with siblings with ASD. For example, their participants reported that their sibling with ASD taught them unconditional love, patience, or that people with ASD are like others. The participants in this study all shared that they see the world differently and that they understand that not everyone sees the world as they do. "Not everything is what it seems," to quote Jessica.

Three of the participants reported doing their own research into ASD. Each reported doing research in an effort to understand and connect with her sister. Doing their own research into ASD led to good yet unforeseen experiences. One participant explained that she has become a kind of spokesperson for ASD to her friends and those around her. Another woman reported

that her research into ASD gave her an academic outlet, as she would do projects in school about ASD and participate in programs like Autism Speaks. A third woman reported that her research into ASD has led to treatment for her sister and to the interviewee herself seeking a career in counseling. Humorously, nearly all the participants talked about having developed the ability to spot ASD in others instantly. Their individual research into ASD provided a platform for the women to give back to the larger autism community. They came to understand their sisters while at the same time understanding the disorder better. They put their own wealth of information about ASD to work by helping others and meeting needs within their own communities.

All four subjects reported that having a sister with ASD shaped who they have become professionally. One participant shared that she had become a teacher to help kids with academic needs. Another woman talked about becoming a counselor for people with ASD. A third interviewee discussed using the listening skills she has developed in her daily profession. Helping seems to have become a driving force in the lives of these women. They capitalize on skills they learned growing up with their sisters with ASD. These learned skills, such as de-escalation and coping with their sisters' anger, allow them to face a harsh world, a world full of emotional problems, with a desire to help. Interestingly, all of the career choices mentioned involved talking, likely highlighting the skill set these women have found most effective with their sister with ASD.

Women in this IPA study reported that growing up with a sister who has ASD, they had to develop a variety of additional skills they would not have otherwise had. In addition to the coping skills mentioned above, the participants talked about having to learn skills to help their families and themselves manage the stress from their sisters' tantrums and times of isolation. At times, the woman was parentified and provided direct care for her sister with ASD. At other

times, they served as a type of release valve, as their parents or sisters would take their stress out on them. The interviewees all talked about their sisters using them to manage their stress. One woman shared that her sister would not act out publicly but would save all of her frustration for the family at home. Participants told stories about their sisters being excessively emotional, inappropriately verbal, and physically dangerous when they were stressed. This finding is in line with the work of Ross and Cuskelly (2006), who reported that 84% of their respondents cited aggression as the most common stressor in the sibling relationship. Two of the women relayed stories of being physically assailed as children by their sisters with ASD, while the two other women talked about their sisters taking their frustration out on them verbally. All of the interviewees talked about their sisters with ASD being overly emotional and that the emotionality was inappropriate to the situation.

These circumstances required the women in this study to develop certain coping skills such as conflict resolution skills, distraction skills, using nonfamily social interactions for support, and developing unique hobbies as a part of their own identity development. One of these coping skills was limiting the amount of time spent with the sister who has ASD. Three of the four women reported that they currently limit the amount of time they spend with their sisters because of their inappropriate emotional presentation. Two participants talked about rarely visiting their family now. This physical separation seems to serve the purpose of giving the women an emotional break from their sisters. One interviewee described having to shut herself down emotionally to be around her sister and that she does not like having to do that, so she does not visit. Another woman talked about having the experience as a child of shutting herself off emotionally, which led to some years of emotional distance from her family. The physical and emotional separate appear to serve the same purpose, to help the women cope with their sisters'

emotional presentation. While most women simply distanced themselves from their sisters because of the tantrums, those who were unable to emotionally closed themselves off and avoided their sisters with ASD.

All of the subjects in this study reported that they were treated differently than their sisters with ASD. One participant reported that she felt like she was an only child because of how her parents treated her and her sister with ASD. Three of the women reported being parentified, having to provide care for their sisters even as children. This finding is in line with the work of Ward et al. (2016), who found that children were often used as caregivers for their sibling with ASD. Each of the women reported that schedules were modified, social events were attended or abandoned, and resources were used exclusively for their sister. Half of the interviewees reported feelings of neglect while growing up, and three of the four women reported that their parents did things for their sister that they would not have done for them. Though a number of possibilities exist for this discrepancy between sisters, the women in this study took this visage of favoritism as just that, favoritism. They interpreted their parents' actions as choosing their sister over them in many scenarios, including social outings. They carried with them, even into adulthood, feelings of neglect and having their problems seen as less important than their sister's with ASD.

### **Table 5.5**

#### *Summary of the Participants' Interaction With ASD*

Findings	Interpretation
“In what way has having a sister with ASD made you who you are today?”	Women give more grace and have more understanding, understanding that things are not always what they seem
Doing their own research into ASD	Gave women the tools to serve others, outside their home

Sister with ASD shaped who they have become professionally	The women work in fields where they can continue to be helpful, as they were at home
Having developed a variety of additional skills	Helped women deal with their sister with ASD
Limiting the amount of time spend with their sister who has ASD	Helped women with their own emotional health
Women being treated differently than their sister with ASD	Led to feeling neglect, feeling less important than their sister with ASD

### **Autism and the Family**

Three quarters of the subjects talked about recognizing, even as children, that their family was different because of their sister with ASD. Though all of the women acknowledged that they recognized that their sister with ASD was different than other girls, three of the four also saw that their family was different than other families. These women reported that their parents were noticeably different than their friends' parents. The participants reported that their family was less socially outgoing than other families. From the women whose sisters were diagnosed as children, there was an explicit focus on ASD as an identifier for the family. When other families were engaging in school activities or sports, their families were participating in Autism Speaks and other autism awareness programs. Most women saw these differences as negative. Their experiences with their families of origin were uncomfortable and caused them to pull away from their families at points. These differences were due in part to family mental health history.

Three of the four women reported diagnoses within their family of origin, and specifically, they reported that they had another family member with developmental issues: father, mother, or brother. Some required treatment, while others were undiagnosed; however, all problems were severe enough to cause problems for that family member. Research conducted by Schultz et al. (2012) found that families of individuals with ASD suffer from stress-related disorders, and Ozonoff et al. (2011) found that the recurrence rate of ASD in younger siblings

was 18.7%, suggesting that more than one out of every six children with ASD who have a younger sibling has a sibling with ASD. The presence of emotional disorders within the family of origin raises a number of questions which are beyond the scope of this research, not the least of which is heritability. However, the concern for this work is how these disorders affected the neurotypical woman's observations of and interactions with her sister with ASD. It appears that the participants' awareness of mental health issues was heightened. Women reported an awareness of disorders in members of their families beyond their sister with ASD. The interviewees were able to explain well the symptoms, the consequences, and oftentimes the lack of treatment other members of their family received. Because of her experiences with her sister and family, Jessica laughed, "I can spot autism from a mile away."

However, in spite of these recognized conditions, all four women interviewed reported that their sister's wants, needs, or desires took precedence over others in the family. Shivers et al. (2019) postulated that siblings with a disability create more stress in the family, which leads to attention being taken away from other members of the family. The participants explained that as children, they did not feel they could carry their own hurts or needs to their parents because their parents were already overwhelmed or because their sister with ASD would come and take their parents' attention away. This finding is in line with the work of Ward et al. (2016), whose participants reported that their autistic sibling's wants and needs oftentimes came first. The women in this study felt that their parents went the extra mile for their sister with ASD, even so far as to ask the interviewees to provide some level of care for their sister with ASD, a finding also identified by Cridland et al. (2016) and Ward et al. (2016). This experience of seeing their sister cared for first and most was distressing for the women in this study. They reported frustration with their parents. Those who did broach the subject with their parents were met with

explanations that were deemed not good enough. Instead, they continued to feel “neglect,” according to Emily. Hannah echoed that thought:

There was never enough time to hash out what I was feeling because my sister always needed to do that so, um, I didn’t feel like there was space for me to experience these things, so I just didn’t experience them.

**Table 5.6**

*Summary of Autism and the Family*

Finding	Interpretation
Noticing that their family was different because of their sister	Made the women uncomfortable and want to pull away from their family.
Family mental health	ASD and other mental health conditions were prevalent with in the family of origin.
Sister’s needs took precedence over other family members’ needs	Women were distressed, felt neglected, and repressed their feelings.

### Limitations

Limitations are a recognized risk in all research, both qualitative and quantitative.

Minimizing the impact of inherent limitations was a priority when this study was designed.

Limitations of this IPA study include sample size, use of a single interview session, lack of a pilot study, variables not controlled for, subjectivity, bias, and the structure of the interviews.

Each of these limitations is discussed below.

### Sample Size

Regarding sample size, Smith and Osborn (2008) recommended that for students doing their first IPA study, three participants is an appropriate number because it allows the young researcher to focus on depth, engaging with the subjects, and the material at an appropriately intimate level. A sample size of four participants, made up of a relative homogenous group, is not in and of itself a limitation, but so small a group does not allow the findings of this study to

be generalized. Instead, a limitation of this study is that these findings, grouped as themes, speak to the lived experiences of a very specific group in the population: female, White, educated, from a nuclear family, residing in the southeastern United States, and having a biological sister with ASD.

### **Single Interview Session**

For this IPA study, women were asked about their experiences both presently and growing up with a sister who has ASD. Another limitation of this study was that these women were only interviewed once. Though this is not an uncommon practice, it is possible that richer data could have been gathered if the women had been interviewed more than once. Being that the goal of IPA research is for the researcher to try to make sense of the participants as the participants try to make sense of their own personal experiences, additional interview sessions could have aided in this process.

### **No Pilot Study**

An additional limitation of this study is that it was not piloted to refine the interview questions. Many researchers pilot their work to refine questions or gain insight into how the overall process of research will go (Smith and Osborn, 2008). Though a pilot study is not required, the lack of one may have created an unforeseen limitation. For example, in the first interview, the concluding question, “In what way has having a sister with ASD made you who you are today?” arose in a moment of inspiration. Therefore, this question was not on the interview form given to the interviewees before the interview session. This unexpected question may have created some anxiety for participants because they could not prepare a response before the interview.

### **Not Controlling for Age at Diagnosis in Sister with ASD**

At several points, a difference within the sample became clear. Two of the women talked about their sister being diagnosed in childhood, while the other two women reported that their sisters were diagnosed as adults. This difference manifested in several ways, including how the women and their families acted while the women were growing up. This finding is in line with the work of Roeyers and Mycke (1995), who found that siblings with more information about ASD reported a better relationship with their autistic sibling in childhood. Though this variety in the sample does not appear to have compromised the study, it should be considered a limitation of the study because this apparent divide does suggest that the experiences of these women vary based on when their sister was diagnosed. Richer data could have been gathered if the research method controlled for when the sister was diagnosed, in childhood or adulthood.

### **Factors Not Controlled for in Neurotypical Subjects**

Though only gender and developmental history were controlled for in this study, many other demographic traits were found to be consistent across the sample: race, religion, having been reared in a nuclear family. A limitation of this study was that efforts were not made to control for other factors. Age, birth order, level of education, or where the women were born could have added a depth to this study and given the data a level of specificity it does not have otherwise.

### **Subjectivity**

Another limitation of the work was the inherent subjectivity that comes with qualitative research. The completion of an extensive literature review before beginning research is but one example of how bias can be injected into the work, as it leads the researcher to look for or expect results similar what he has read. Similarly, my extensive experience working with both children

and adults with ASD produced yet another level of inherent subjectivity, as my professional experiences led me to look for or even expect these women to report certain traits in their sisters with ASD. It fascinated me to listen to these women's stories about their sister with ASD and to record for research purposes their lived experiences as women who have a sister with ASD.

### **Single Piece of Research as an Outline for the Interviews**

Finally, a limitation of this IPA study was the use of a single piece of research to outline the interview sessions. All research needs a foundation from which to build. However, existing research on the female autism phenotype is extremely limited, and this study using a single piece of female autism phenotype research as its outline is a definite limitation. Work regarding a female autism phenotype is very young, less than 20 years old, and certain traits of a female autism phenotype, like camouflaging, have only been identified within the past five years. For this reason, I took the most recent and concise work on the female autism phenotype at the time of this dissertation and used it as an outline for this research study; see Hull et al. (2020).

The goal of this IPA study was to determine if recognized themes persist when women with sisters who have ASD are interviewed, and if as-of-yet unrecognized themes might emerge. The interest for this work was what these women with sisters who have ASD might contribute to the understanding of a female autism phenotype.

### **Recommendations**

This IPA study investigated the lived experiences of women who have a sister with ASD using a female autism phenotype as an outline. The goals of this work were to shed new light onto a female autism phenotype, expanding the understanding of this possible phenotype in ASD. This study found both previously identified and new traits of a female autism phenotype.

Using the superordinate themes found in this work, recommendations for future research and practice are presented for consideration.

### **Social Skills Groups**

Social relationships outside the family are an important part of a female autism phenotype (Lai et al., 2011, 2012). However, Holtmann et al. (2007) found that women, more than men, with ASD experienced more social problems, such as difficulty finding and maintaining friendships. Results from this IPA research confirm this finding. This research found that all of the participants' sisters were unable to maintain long-term relationships from childhood into adulthood and that many of their adult relationships were either shallow or not particularly healthy. Therefore, it is recommended that group therapy with a focus on social skills be considered a critical part of the treatment of women with ASD.

### **Family Therapy**

When talking about how having a sister with ASD has made her who she is today, Hannah said, "I've just continued to feel kind of burdened for family members of people on the spectrum, because of—sometimes you just don't know what to do." Therefore, another recommendation from this research is that treatment modalities and treatment efforts be designed to help the families of women who have ASD. Too often, clinical treatment focuses on the identified patient to the exclusion of their caregivers and those closest to them. Instead, the treatment of ASD and other developmental disorders should be family focused, holistic, or systems focused. For example, psychotherapeutic treatments for families with a female with ASD should focus on recognizing the emotional limitations of women with ASD and forming appropriate relationship expectations and boundaries as needed. Also, parent training should

focus on providing care for the non-diagnosed child, considering how the neurotypical sibling is effected by the imbalance in attention.

### **Group Counseling for Siblings**

The participants in this study shared a number of issues that arose from having a sister with ASD. These issues were similar enough to justify treatment using a group modality. I am recommending the use of group counseling in the treatment of these problems-in-living for siblings of women with ASD. The use of a group modality could be helpful in dealing with feelings of isolation or neglect. The group could help in developing coping skills for times when the sibling is with their sister with ASD as well as for times when they are apart. Group could also provide a safe place to share feelings and exchange ideas for dealing with additional problems-in-living.

### **The Importance of Shared Interests**

Shared interests were a more prominent subject in the interviews than restricted or repetitive interests. Future research into a female autism phenotype should consider the value of women's shared interests with those closest to them. Though restricted or repetitive interests are a key part of the nosology of ASD, a consideration of shared interests appears appropriate in the diagnosis of females with ASD.

### **Understanding Co-occurring Diagnostic and Nondiagnostic Conditions**

Internalizing problems like co-occurring disorders and nondiagnostic behavioral issues were reported by all four interviewees. Though research has consistently found that women with ASD often have another diagnosable condition like depression or anxiety, a firm link such as causation has not been established. Future research should consider why depression and anxiety are common co-occurring disorders with ASD and if the reason is nosologically important. Also,

future ASD nosology should consider current nondiagnostic behaviors such as camouflaging and tantrums in the diagnosis of ASD.

### **Research on Camouflage as a Part of Treatment**

Camouflaging has become a popular topic in ASD research within the past five years (Dean et al., 2017; Lehnhardt et al., 2016; Rynkiewicz et al., 2016). Despite its relatively young age, this theory is proving to be useful in both diagnosis and research. Continued research into camouflaging and its place in treatment will prove invaluable. Capitalizing on this research on camouflage in counseling may mean using the desire to appear neurotypical to teach daily living skills and promote interpersonal growth. Camouflaging may open the door to unique treatment options based on the autistic individual's desire to conform and be accepted socially.

### **Individual Counseling for Women Who Have a Sister with ASD**

This work looked at the lived experiences of women who have a sister with ASD. Therefore, this sixth recommendation is for treatment modalities for women and men who have a sibling with ASD. Three of the four women talked about participating in their own counseling at some point in their life, and all of the women reported interpersonal, familial, and extra-familial relational issues. Insofar as the issues at hand are related to the woman in therapy, counseling should be considered for problems-in-living, including having a sister with ASD.

### **Psychoeducation**

Psychoeducation has proven useful in facilitating growth within the family, according to the interviewees. Roeyers and Mycke (1995) found that siblings with more knowledge about ASD reported a more positive relationship with their autistic sibling. Therefore, it is recommended that families be encouraged to seek out information about ASD, even before formal diagnosis. Practitioners and researchers should always encourage those looking for

information about ASD to seek professional help. However, a wealth of information is available online, in books, and from groups that specialize in organizing activities for families with members who have ASD.

### **Reflections on the Research Experience**

Words fail to express the intense emotions I feel surrounding this research and its findings. At the beginning of my PhD program, I was told that the dissertation process was extremely difficult and would require considerable time and effort. I found this to be true in more ways than one. There were times when the research process was slow and I could only wait, while at other times, there was too much to do and not enough time to do it. Between interviews and data analysis, this research process has been an extremely taxing yet wonderful experience.

The research topic started out very broadly, and repeatedly, I found areas of interest had already been investigated. Finally, I came across an article by Marciano et al. (2015) who had investigated the lived experiences of married couples who had a child with autism. My thought was, “What about siblings?” I quickly found that that research had already been done. Moving forward, I found work by Baron-Cohen (2002) on the extreme male brain theory, which led to Hull et al.’s (2017, 2020) work and the burgeoning research area of a female autism phenotype. My heart turned to the siblings of all of those individuals with ASD I had treated over the years. What could their experiences with their sibling who has ASD tell me about autism? I was actively looking for those areas of autism that had not been researched, so I put the two topics together: sibling reports on females with ASD. This was quickly refined to women’s experiences of having a sister with ASD with a focus on a female autism phenotype.

In short order, I went from a research topic to Institutional Review Board approval and emailing flyers to all of the clinics I was associated with in the Atlanta metropolitan area. I

anxiously waited for women to email me to volunteer to participate in my research project. I prayed patiently for an opportunity to interview women with a sister who has ASD, and overnight, it seemed, I went from famine to feast. I had a new subject to interview every week and no time to transcribe. The stress had changed from no research participants to no time to keep up with research participants. The energy was new and fresh, and soon I had the data in hand and analysis began. Finding themes in the work was enjoyable; however, there was so much data that even after several weeks, I felt like I might be missing things. The outline by Hull et al. (2020) helped me focus the data and stay on topic: what women with sisters who have ASD can teach me about a female autism phenotype.

Transcribing, finding themes, bracketing off additional material, deducing additional themes, excluding material beyond the scope of this research project, and analyzing the data turned from hours of work to weeks of work. Smith and Osborn (2008) stated that IPA takes an incredible amount of time between the interviews and the analysis, but I did not comprehend the weight of the interviews until I began analyzing that first transcript.

Though the work of data analysis was a great weight on me, the emotional experiences of the women impacted me most. During the course of the interviews, I expected to hear stories of good times and quirky behaviors. I expected these women to talk about trying too hard to get their sister with ASD to appear neurotypical. Instead, I heard these women pouring out their hearts, talking about not understanding, and sharing with me how they were hurt by their sister. For example, Ashley, talking about wanting a relationship with her sister, said, "It's a relationship in the sense that it exists, but I don't think it would be very, by normal standards, it's not particularly satisfying or deep. It hurts to even say that out loud." They talked about not getting attention from their parents when they needed it most, such as when Jessica said,

As I got older and started having different issues and stuff, I felt like, okay, don't be, like, another problem. You know, like, I didn't want to come to my parents and be like "Hey, I kinda hate my life." [laughing] At some point and, you know, I just kind of dealt with it on my own."

At the same time, the women in this study talked about how they were shaped by their sister with ASD. They shared stories of helping others with their knowledge of ASD and choosing a profession where they could be of benefit to people with emotional needs. The women in this study talked about having learned to give grace and understanding to others because of growing up with their sister who has ASD. These stories forced me to take a step back and ask myself how women with sisters who have ASD could have been so ignored by professional helpers like myself.

This emotional rollercoaster for me is but a taste of the life these women lead with their sisters who have ASD. I am reminded that all of life is like this, mountaintops and valleys low, constant ups and downs. However, I have faith that difficult times will come, but they will not last. To quote Gandalf from *The Lord of the Rings: The Return of the King*, "No, the journey doesn't end here." "The grey rain-curtain of this world rolls back, and all turns to silver glass, and then you see it." "White shores, and beyond, a far green country under a swift sunrise." (Jackson, 2003) Therefore, "let us run with endurance the race that is set before us, looking until Jesus, the author and finisher of our faith..." (New King James Bible, 1991, Hebrews 12:1-2)

### **Chapter Summary**

This chapter presented the interpretations of the findings from the four interviews of women who have a sister with ASD using the six superordinate themes found in the interviews. These six themes were social relationships, interests, internalizing problems, camouflaging, the

women's interaction with ASD, and autism and the family. Additionally, in this chapter, limitations of the work were discussed, including demographics, generalizability, sample, and subjectivity. Recommendations were made based on the results of this work for future treatment and research. Finally, I reflected on my experience of having completed this IPA research project.

### **Study Summary**

Throughout this work my goal was to better understand women who have a sister with ASD. I believed that symptoms of ASD were unique enough in females to justify a distinct phenotype, a relatively new concept in the diagnosis and treatment of ASD. Using the research methods of interpretative phenomenological analysis and semi structured interviews I was able to gather data from four adult women who had a sister with ASD. Their reported experiences gave support for the theory of a female autism phenotype.

I began this study researching the existing literature on ASD in females. I found that only a few authors had published work exclusively on females with ASD and that a very small group of researchers had hypothesized the existing of a unique female autism phenotype. Throughout this limited body of research attention had been given to females who were chiefly children. Little research existed on adult women with ASD. Additionally, the primary informants in those studies were either the female herself or her parents. Almost no data had been collected from siblings.

At this point I posited that women who have sisters with ASD would be able to provide valuable insight into a theorized female autism phenotype. I put out a call for participants and accepted four volunteers who each sat for an hour-long interview about their relationship with their sister who has ASD. Results were consistent with the findings of other studies, traits of a

female autism phenotype were identifiable from the interviews, including significant and specific issues with social relationships, interests that were odd but that did not necessarily interfere with daily functioning, internalizing problems like anxiety, depression, and eating disorders, and camouflaging or presenting as neurotypical. The interviews also produced two additional findings worthy of attention, the neurotypical sister's interaction with ASD and autism and their family.

I concluded my work by recommending that future practitioners and diagnosticians consider a female autism phenotype as a part of practice and treatment. I believe that counselor educators and researchers should continue to investigate the limits of this unique phenotype and its application in the field of counseling and psychology. Additionally, I stated that ASD should be understood as a disorder affecting the family system. I recommended that practitioners and researchers see siblings and their parents as part of the overall clinical picture and that they be included in both the diagnostic process and treatment phase. Finally, I concluded with a review of this work and I drew the connection between the daily struggles of having a sister with ASD and how life will always challenge us, but we have hope that "...joy will come in the morning." (New King James Bible, 1991, Psalms 30:5)

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## APPENDIX A: Individual Interview Questions

Based on Hull, Petrides, & Mandy, 2020

Script: *“I am going to ask a variety of questions about you and your sister with autism. With each question think about now and in the past. Think about a specific instance or event and tell me that story if you can. I am wanting to know about your perspective to each situation and no one else’s. Do you have any questions before we begin?”*

Interpretative phenomenological analysis question: How does having a sister with autism affect her and your relationship with her?

### Social Relationships

1. **Primer:** What is your relationship like with your sister who has autism?
2. What are your sister’s relationships with others outside the family like?
3. What benefits or drawback, if any, comes with your sister’s relationships?

### Interests

1. **Primer:** Do you share any interests with your sister who has autism?
2. What interests does your sister with autism have, if any?
3. What benefits or drawback, if at all, comes with your sister’s stated interest?

### Internalizing Problems

1. **Primer:** Does anyone else in your family have a diagnosis?
2. Does your sister with autism have any other psychological, emotional, or behavior challenges? If so, what are they?
  - a. Anxiety?
  - b. Depression?
  - c. Eating Disorders?

3. How do(did) these other diagnoses effect your relationship with your sister?

### **Camouflaging**

1. Primer: Does your sister with autism act differently around others than she does around you?

In what ways?

2. What things does your sister with autism do to appear normal to others?

3. What things does your sister with autism say to sound normal to others?

## APPENDIX B: Consent Form

### Consent Form

William G. Carroll

Liberty University

Center for Counselor Education and Family Studies

### Consent

**Title of the Project:** Sister-to-Sister: A phenomenological study of women's experiences of having a sister with Autism Spectrum Disorder based on the female autism phenotype.

**Principal Investigator:** William Carroll, MA, LPC, Liberty University

#### Invitation to be Part of a Research Study

You are invited to participate in a research study. In order to participate, you must be female, age 18 years or older with a biological sister who has previously been diagnosed with Autism Spectrum Disorder. Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

#### What is the study about and why is it being done?

This study is being conducted in partial fulfillment of William Carroll's Ph.D. dissertation. The purpose of this research is to determine what unique characteristics sisters of females with autism report in their relationship with their sister with Autism Spectrum Disorder. The researcher is seeking a greater understanding of the lived experiences of women who have a sister with Autism Spectrum Disorder.

#### What will happen if you take part in this study?

If you agree to be in this study, I would ask you to do the following things:

1. First, set aside 1 to 2 hours for the day of the interview. Remember this interview will be audio recorded.
2. Second, when you arrive at the interview site, have a seat in the waiting area, Mr. Carroll will be with you at the scheduled hour.
3. Third, if you are unable to make your appointment please call or email Mr. Carroll as soon as possible to reschedule.

#### How could you or others benefit from this study?

Participants should not expect to receive a direct benefit from taking part in this study.

#### What risks might you experience from being in this study?

The risks involved in this study are minimal, which means they are equal to the risks you would encounter in everyday life. However, if you report physical abuse, sexual abuse, neglect, or the maltreatment of others, by state law William Carroll, LPC is required to report these issues to the

Georgia Department of Family and Children's Services. Additionally, if you report a desire to harm or kill yourself you will be referred for immediate in-patient treatment.

#### **How will personal information be protected?**

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher will have access to the records. If data collected from you is shared, any information that could identify you will be removed before the data is shared.

- All data will be coded by number to protect the privacy and confidentiality of all participants. Demographic data will be stored separately from interview data. All interview and demographic data will be stored on external hard drives so it will be inaccessible via the internet. All interviews will be conducted in a location where others will not easily overhear the conversation.
- Data will be initially collected on computer. It will be stored on external hard drives. Each of these external hard drives will be stored in separate locations, inside locked safes. After three years all data will be disposed of by first deleting the digital data off of the external hard drives and then by destroying the physical drives. There is no anticipated use of the data in other studies and only the results published will be retained for future presentations.
- The interview session will be audio-visually recorded and transcribed. The audio-visual recordings will be stored on external hard drives. The hard drives will be stored separately in locked safes for three years and then be erased and physically destroyed. Only the researcher will have access to the external hard drives and the safes where they are stored.
- The researcher cannot guarantee total unanimity. If you report physical abuse, sexual abuse, neglect, or the maltreatment of others, by state law William Carroll, LPC is required to report these issues to the Georgia Department of Family and Children's Services. Additionally, if you report a desire to harm or kill yourself you will be referred for immediate in-patient treatment.

#### **Is study participation voluntary?**

Participation in this study is voluntary. Your decision whether to participate will not affect your current or future relations with Will Carroll, LPC. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

#### **What should you do if you decide to withdraw from the study?**

If you choose to withdraw from the study, please contact the researcher at the email address/phone number included in the next paragraph. Should you choose to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

#### **Whom do you contact if you have questions or concerns about the study?**

The researcher conducting this study William Carroll, LPC. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact Mr. Carroll. You may also contact the researcher's faculty sponsor, Dr. Kevin Hull, Ph.D.

**Whom do you contact if you have questions about your rights as a research participant?**

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA 24515 or email at [irb@liberty.edu](mailto:irb@liberty.edu)

**Your Consent**

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

*I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.*

The researcher has my permission to audio-record me as part of my participation in this study.

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Printed Subject Name

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Signature & Date

**APPENDIX C: Demographic Questionnaire**

Sister to Sister: a phenomenological study of female's experiences of having a sister with Autism Spectrum Disorder based on the Female Autism Phenotype.

**INSTRUCTIONS**

Please complete the following demographic information. Note that all personal information will be kept completely confidential and none of the responses you provide will be connected to your name, email address, or other identifying information. Thank you for your time

1. Name.

2. Contact Information (phone/email)

3. Age.

4. Ethnicity.

- African American/Black
- Hispanic/Latino
- First Nations/Inuit/Alaskan Native/American Indian
- Asian
- White
- Other

5. Do you and your sister with Autism Spectrum Disorder currently reside together?

- Yes
- No

6. How many years have/did you and your sister reside together?

7. Please provide any additional information you would like the researcher to know about you.

A large, empty, light blue rectangular box with a 3D effect, intended for providing additional information. The box has a subtle gradient and a slight shadow, giving it a three-dimensional appearance. It is positioned horizontally and occupies a significant portion of the page's width.