ABSTRACT

THE ADULT SIBLING'S EXPERIENCE OF AGGRESSIVE BEHAVIORS IN CHILDREN WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE STUDY

By

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This study explored adult siblings' experiences growing up in a home with a sibling diagnosed with autism spectrum disorder (ASD) by talking to the siblings directly. Additionally, this study examined what, if any, impact the physical aggression exhibited by the child with ASD had on the siblings' childhood. The researcher developed an interview guide and conducted one on one interviews with 13 siblings of children with ASD who exhibited aggressive behaviors.

The study found that the participants felt unequipped to handle the aggression, were often anxious in their home due to the unpredictability of the behaviors, and felt overlooked during their childhood. The participants also spoke of many rewarding aspects of having a sibling with ASD including learning patience and compassion from a young age and feeling pride in their sibling's accomplishments. Recommendations for supporting this specific population are outlined. Implications for social work practice are also discussed.

THE ADULT SIBLING'S EXPERIENCE OF AGGRESSIVE BEHAVIORS IN CHILDREN WITH AUTISM SPECTRUM DISORDER:

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For Lennon and his family, who helped me find my passion for this field.

TABLE OF CONTENTS

Page

CHAPTER

CHAPTER Page

Page

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disability that affects 1 in 68 children in the United States (Centers for Disease Control and Prevention [CDC], 2014). With the current estimate of ASD showing a 30% increase since 2008 and a 60% increase since 2006 (CDC, 2014), the prevalence of ASD is growing every year and impacting more families than ever before.

There is no known cause of ASD but researchers now agree that there appears to be a combination of environmental and genetic factors that make an individual more at risk for the disorder (CDC, 2014). The most common risk factors include having a sibling with ASD, low birth weight, and older parental age (American Psychiatric Association [APA], 2013). Furthermore, ASD is 4 times more likely in males than in females and while it is present in all ethnic and socioeconomic groups, it is most commonly identified in White children (CDC, 2014).

Individuals diagnosed with ASD typically display significant social, communication, and behavioral deficits (APA, 2013). Some of these deficits can include having a language delay, failing to initiate or maintain social interactions, engaging in repetitive motor movements, and having rigid schedules (APA, 2013). While it is not a behavior that is required to receive a diagnosis of ASD, many individuals with ASD also exhibit physical aggression (Kanne & Mazurek, 2011; Mazurek, Kanne, & Wodka, 2013). The reasons for this behavior can include frustration caused by communication difficulties, as an attempt to escape an undesired activity, and as a way of gaining access to tangible items such as food or a favorite toy (Matson & Adams, 2014).

The impact of aggression on family members has yet to be thoroughly researched (Hastings & Petalas, 2014; Macks & Reeve, 2007; Petalas, Hastings, Nash, Dowey, & Reilly, 2009). One population that is often overlooked, that experiences the effects of this behavior in their home on a daily basis, are the typically developing (TD) siblings. In comparison to the research that focuses on the parents' perspectives of having a child who has ASD and exhibits physical aggression tendencies, the quantitative and/or qualitative literature is almost non-existent in its examination of the TD siblings' experiences. Due to the fact that the number of families who are impacted by ASD is increasing, research in this area is warranted.

Purpose of the Study

The purpose of this study was to better understand the unique experiences individuals have growing up with a sibling who has ASD and displays aggressive behaviors towards others. Using an adult sibling perspective, this research explored how the aggression impacted their childhood and the ways they felt that experience has influenced who they are today.

Definition of Terms

Autism spectrum disorder (ASD): Classified in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; APA, 2013) as a developmental disorder that is "characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships" (p. 31).

Typically developing (TD) child: A child that does not have a *DSM-5* diagnosis and is considered to be developmentally normal.

Physical aggression: Hitting, biting, scratching and other acts of physical harm directed at another person (Mazurek et al., 2013).

Siblings of children with ASD: A person who has at least one sibling diagnosed with ASD by a professional and meets the *DSM-5* criteria.

Social Work and Multicultural Relevance

Given the fact that there is limited research specifically on the impact of aggression on TD siblings of children with ASD, little is known regarding the experiences of this population. Additionally, there is an extreme lack of research with culturally and ethnically diverse populations. By asking open-ended interview questions, the hope is to gain a more comprehensive picture of the TD sibling's experience. As a result, this study will aid social workers who encounter this population understand how to better support them. Given that ASD is becoming more prevalent every year, it is important that services are offered to every family member affected by the disorder, not just the child with ASD and the primary caregiver.

CHAPTER 2

LITERATURE REVIEW

This literature review consists of five sections. The first section describes aggression in children with ASD, the implications of this specific behavior on the family, and common treatments for aggression in children with ASD. The second section discusses the impact of ASD on the family unit as a whole. The third section outlines the impact of ASD on the TD siblings specifically including their general perceptions, the positive effects seen of having a brother or sister with ASD, as well as the adverse effects. The fourth section describes the impact aggression has on the TD sibling. This section outlines what the parents perceive the impact to be on the TD siblings, what the TD siblings themselves perceive, and the correlation found between the rate of problem behavior in children with ASD and their sibling psychological adjustment. Finally, the fifth section discusses the limits of the current literature on the impact of aggression on TD siblings.

Aggression

One specific behavior often exhibited by children with ASD is physical aggression, typically manifested by hitting, biting, scratching and other acts of physical harm directed at another person (Mazurek et al., 2013). This section will outline the prevalence of aggressive behavior in child with ASD, possible causes of aggression and in what circumstances aggression is most often exhibited and the added difficulties often associated with aggressive behaviors. The section will then discuss further implications of aggressive behavior in children with ASD such as the risk of discrimination, the amount of stress on the family caused by the behavior, and the necessary accommodations that families often have to make.

Studies have found that aggression presents in approximately 53-56% of children with ASD across the United States and Canada (Kanne & Mazurek, 2011; Mazurek et al., 2013). While aggression is often present in other childhood diagnoses such as attention-deficit hyperactivity disorder (ADHD), anxiety disorders, intellectual disability (ID), and traumatic brain injury (TBI), the level of aggression exhibited by children with autism is higher (Farmer & Aman, 2011; Matson, Wilkins, & Macken, 2009; Mayes et al., 2012). Similarly, Brereton, Tonge, and Einfeld (2006) found that children diagnosed with ASD had more disruptive behaviors than children with an intellectual disability, including tantrums and abusive actions.

While there could be several reasons a child with ASD has aggressive behaviors, there are certain factors that may increase the risk for the child exhibiting such behavior. Bronsard, Botbol, and Tordjman (2010) compared 74 individuals with ASD and 115 TD individuals who were matched in age, sex, and puberty stage. According to parent and caregiver report, the individual with ASD most commonly displayed physical aggression out of frustration, anger, or opposition. Furthermore, individuals with ASD showed significantly higher rates of physical aggression than TD individuals when placed in stressful situations. The researchers attributed this difference to the fact that many children with ASD are unable to regulate their emotional responses. Additionally, children with ASD often have significant impairments in their ability to communicate their stress and emotions verbally, which can result in them releasing their stress through physical aggression (Bronsard et al., 2010). Conversely, the TD individuals in the study were able to release their stress by employing coping strategies, expressing their stress verbally, and utilizing social interactions with those around them to seek comfort.

In a similar study, Mazurek and colleagues (2013) conducted a large-scale quantitative study in an effort to thoroughly describe the prevalence and various features associated with physical aggression in children with ASD. Participants consisted of 1,584 children with ASD and were recruited through a national ASD database. Physical aggression was associated with greater difficulties with social skills, communication skills and sensory problems when compared to both children with ASD without aggressive behaviors and a normative sample. Additionally, children with ASD who also have aggressive behaviors have higher levels of sleep problems, gastro-intestinal problems, and self-injurious behaviors. Furthermore, over half of the participants were shown to continue to exhibit physically aggressive behaviors as they aged. This is noteworthy in that as the child with ASD grows in size the impact on their victims may have greater consequences (Mazurek et al., 2013).

As the severity of ASD increases, the rate of physical aggression increases as well (Matson & Rivet, 2008; Matson et al., 2009). In a study of 365 children with ASD, Farmer and Aman (2011) found individuals categorized as low functioning had higher rates of physical aggression that individuals who were considered to be higher functioning, such as children classified having a *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV*) diagnosis of Asperger’s syndrome.

The presence of challenging behaviors, such as physical aggression, places the child with ASD at an increased risk of being discriminated against. For instance, individuals who exhibit high levels of challenging behaviors are often forced into social isolation due to difficulties in predicting and controlling such behaviors in public (Buschbacher & Fox, 2003). These behaviors may lead to unsuccessful adaption in the community such as the individual not being able to complete routine tasks required in daily life like grocery shopping and driving. As a result of these challenges, individuals with challenging behaviors often face stigma from the general population (Lecavalier, Leone, & Wiltz, 2006).

The occurrence of aggressive behaviors in a child with ASD can impact the family in such a way that often times more extensive adjustments have to be made (Lecavalier et al., 2006). The reality of the burden of physical aggression in the home makes it one of the top cited reasons for residential placement (Cowley, Newton, Sturmey, Bouras, & Holt, 2005; McCurdy & McIntyre, 2004). In a study conducted by McIntyre, Blacher, and Baker (2002) families were recruited from the Southern California Regional Centers database. Parents of 103 children with developmental disabilities completed assessments regarding their child's maladaptive behaviors, adaptive functioning, and impact on the family unit. The researchers discovered that a high rate of maladaptive behaviors in the child with a disability was a significant predictor of families seeking residential placement for the child. Additionally, maladaptive behaviors were significantly correlated with maternal stress and family stress as a whole (McIntyre et al., 2002). Furthermore, a study of teachers and parents of 293 children with ASD found physical aggression was the highest cited concern and indicator of stress for both parents and teachers (Lecavalier et al., 2006).

Common Treatment for Aggression in Children with ASD

For years, there has been a great deal of debate as to which treatment for ASD is the most effective (Matson & Williams, 2015). Given the fact that the cause of ASD is still unknown, leaders in the field have yet to create a pharmaceutical treatment and have thus been required to rely on behavioral treatments instead (Matson & Williams, 2015). Research has shown that the most effective, and therefore most commonly used, treatment for ASD is applied behavior analysis (ABA; Dawson & Bruner, 2011; Maglione, Gans, Das, Timbie, & Kasari, 2012). The treatment has become so widely accepted that the state of California recently implemented a policy that required all insurance providers, including Medi-Cal, to cover ABA services (U.S. Department of Health and Human Services, 2014).

Applied behavior analysis is based on the concept that behaviors that are reinforced will increase while behaviors that are ignored will decrease over time (Cooper, Heron, & Heward, 2007). Behavior analysts first assess what happens in the child's environment immediately before and after the targeted behavior to create a hypothesis as to why that child exhibits that particular behavior. They then create a behavior plan that will appropriately aim at increasing the child's desired behaviors and decreasing their maladaptive ones (Cooper et al., 2007). For example, working under the assumption that children with ASD often use physical aggression to gain attention, one of the most common treatments for this behavior is to ignore it and to teach the child a more functional way of gaining attention (Buschbacher & Fox, 2003).

This treatment is usually run by professionals but involves the parents in every session and often times the siblings as well (McNellis & Harris, 2014). Family member involvement entails observing the professionals interact with the child with ASD in order to implement the behavior plan correctly themselves outside of the session time. Session time is also a good opportunity for various family members to practice implementing the behavior plan with the professional present so that they can receive feedback on their interactions (McNellis & Harris, 2014). Additionally, in the case that the child with ASD exhibits problematic behavior that requires multiple people to successfully execute the behavior plan, such as needing to restrain a child that is a danger to themselves or others, all family members are expected to be available to help (Harris & Glasberg, 2012).

While parents are most often the family members involved in ABA sessions, TD siblings often play a role as well (Moyson & Roeyers, 2011). The TD sibling's expectations during ABA sessions vary greatly. They may be required to implement certain programs themselves. For example, the TD child may practice assisting their sibling with ASD in brushing their teeth or may have to be available for a peer interaction program. They may also be asked to assist during tantrums or be asked to hypothesize what the child with ASD is trying to communicate when the behavioral therapists and parents are unsure. Other times the TD sibling may be asked to take over more household chores, such as cooking dinner or cleaning, since their parents are preoccupied with sessions or simply to make themselves scarce as to not interfere with the ABA session (Moyson & Roeyers, 2011).

In order for ABA treatment to be most effective, best practice dictates that a clearly outlined behavior plan is consistently followed at all times by all individuals interacting with the child with ASD (Cooper et al., 2007). This is especially true when the child's behavior with ASD is so severe that it can be a danger to his or her TD siblings. In those instances, it is often looked at as crucial to involve the TD siblings in order for them to become better prepared to deal with such behaviors (Moyson & Roeyers, 2011).

The average amount of time a child with ASD has ABA services is between 25-40 hours per week (Valentine, 2010). Some of those hours take place in the classroom during the school day and the remaining takes place in the child's home. Applied behavior analysis home sessions typically last between 2 to 3 hours and are conducted 5 to 6 days a week. This time commitment understandably has a significant impact on the family's time, stress, finances, and quality of time (Cebula, 2012).

In a study by Grindle, Kovshoff, Hastings, and Remington (2009), 53 parents were interviewed about the impact of ABA services on their family members. Over three quarters of the parents interviewed could identify benefits of the ABA sessions for the TD child. These benefits included the TD sibling finding enjoyment in being involved in the sessions when allowed and having an opportunity to learn more about ASD and ways to interact with their brother or sister. However, over one-third of the parents also reported challenges for the TD sibling. Some of those challenges were the TD sibling struggling with all the attention that was given to the child with ASD due to the multiple people that would come to work with them daily. Additionally, in the cases where TD siblings were not needed to assist, they were often required to stay out of the room where the parents were with the ABA instructors and the child with ASD in order to keep them safe during aggressive tantrums. This exclusion had a tendency to make the TD sibling feel isolated from the rest of their family. Moreover, one-third of the parents also reported their own relationship with the TD child deteriorated because of the ABA services due to the amount of time required to implement the behavior plans.

Given the complex nature of human behavior, the created behavior plans can sometimes feel contradictory to common sense. Typically developing siblings of children with ASD are often aware of these complexities of behavior modification at a very young age. In a study that asked TD siblings about their experiences, several reported being able to ignore their sibling's physically aggressive behavior because they had been taught that paying attention to it would only make it worse, a task that is not easy for most children (Moyson & Roeyers, 2011). The reasons for asking someone to ignore their sibling's annoying, inappropriate, or hurtful behavior can be difficult to justify and explain to a young child. Moyson and Roeyers (2011) found that although TD children knew it was best to ignore their sibling's maladaptive behavior, several admitted to retaliating back when no one was looking.

Impact of ASD on the Family

Research has shown that having a child with ASD significantly impacts the entire family system (Angell, Meadan, & Stoner, 2012; Chan & Goh, 2014). This section will describe the accommodations family have to make when they have a child with ASD, the stress families experience, and families' quality of life as a whole.

Given the nature of the disorder, families often have to rearrange many aspects of their daily life to accommodate the behaviors of the child with ASD and their child's various services (Lecavalier et al., 2006). Additionally, research has shown that parents of children with ASD report higher levels of stress (Lecavalier et al., 2006), are at risk for higher levels of mental health difficulties (Manning, Wainwright, & Bennett, 2011; Meyer, Ingersoll, & Hambrick, 2011), and report higher levels of depression than parents of TD children (Benson & Karlof, 2008; Hastings et al., 2005; Steijn, Oerlemans, Aken, Buitelaar, & Rommelse, 2014).

Rao and Beidel (2009) conducted a quantitative study of 15 parents of children with ASD and 15 parents of TD children. Compared to the normative sample of families that did not have a child with ASD in their family, parents of children with ASD reported higher levels of stress and impaired family functioning. The families with a child with ASD in them were found to have a diminished amount of support within the family, were not as self-sufficient in decision making, and less importance was placed on the family system as a whole.

Aiming to assess family quality of life, Davis and Gavidia-Payne (2009) recruited 64 families of children with ASD. Interestingly, the strongest predictor of family quality of life was the amount of family-centered professional support the parents felt they had. Family's income level was also positively correlated with the family's quality of life. One possible reason for this may be that families with more wealth may have access to more professional resources, which was found to increase quality of life (Davis & Gavidia-Payne, 2009). Additionally, family quality of life and emotional well-being was impacted by the extent of problem behaviors in the child with ASD. In accordance with other research, the higher the level of maladaptive behaviors exhibited by the child with ASD the lower the parents reported their own emotional well-being to be.

In a study by Lyons, Leon, Roecker Phelps, and Dunleavy (2010), 1,110 mothers of children with ASD were recruited from a national autism online database. The purpose of the study was to examine caregiver stress, depression, and quality of life. The children with ASD that had the highest levels of ASD symptomatology, such as social and communication limitations and repetitive behaviors, were most likely to have a mother that was seeking treatment for depression. Furthermore, even the mothers of these children that were not in treatment for depression were more likely to report negative impacts on their lives than mothers of children with fewer ASD behaviors.

Mothers with both a child with ASD and a TD child who has significant levels of depressive symptoms often were not as skilled at balancing demands of several children. As a result mothers were unable to model adequate coping skills, potentially impacting the adjustment of TD siblings (Meyer et al., 2011).

Impact of ASD on Siblings

Typically developing siblings of children with ASD are often unnoticed in their families (McCullough & Simon, 2011). Some common experiences they face are feeling embarrassed by their sibling's behaviors, having difficulty with other people's attitudes toward their sibling, the burden of having added responsibility of caring for their sibling, and worrying about what the future would hold for their sibling (Mascha & Boucher, 2006). Siblings also experience the conflicting emotions of sadness versus joy over their differences, pride versus embarrassment, and contentment versus a desire for their siblings with ASD to be typical (Angell et al., 2012). This section will first include the sibling's general perceptions and feelings of what it is like to have a brother or sister with ASD. Next, the research that concluded that TD siblings generally have a positive experience being a sibling to a child with ASD will be discussed. Finally, this section will cover the adverse effects and negative experiences of having a sibling with ASD.

General Perceptions

Typically developing siblings of children with ASD encounter different experiences in their daily lives including not knowing how to describe the diagnosis to others (Moyson & Roeyers, 2011), feeling overlooked in their own family (McCullough & Simon, 2011), not being able to participate in as many extracurricular activities as the general population (Barak-Levy, Goldstein, & Weinstock, 2010), and having more responsibilities than children without a sibling with a disability (Petalas, Hastings, Nash, Dowey, & Reilly, 2009).

In a study of 17 TD siblings of children with ASD, Moyson and Roeyers (2011) investigated the siblings' self-reported quality of life. The most significant theme that emerged was the impact of the invisibility of ASD. Due to the fact that ASD has no physical markers, children with ASD most often look like TD children to a passerby. While this invisibility has positive implications, such as others not staring at them, there were some negative effects as well. By not having a physical attribute to point out to help explain ASD, TD siblings often experienced doubt from their peers, which resulted in feeling misunderstood. Additionally, the TD sibling participants reported dealing with friends not wanting to come over because of the sibling with ASD's behaviors as well as frustration when they were not able to communicate with their sibling themselves. The TD siblings also were found to desire more time at home without their sibling with ASD in order to have time to do activities with the rest of their family that they are unable to do when the child with ASD is present (Moyson & Roeyers, 2011).

Sometimes categorized as *overlooked* (McCullough & Simon, 2011), the siblings often are required to take on a larger caregiver role in the family than what is expected in families without a child diagnosed with ASD. Parents have different behavior expectations for them than for their siblings with ASD (Chan & Goh, 2014). Moreover, families with a child diagnosed with ASD are often focused on the child with ASD because of their complex needs, resulting in less time and attention given to the sibling (Chan & Goh, 2014).

In a study conducted in Israel, Barak-Levy and colleagues (2010) compared 27 TD siblings of children with ASD with 27 siblings of children without a disability. The researchers discovered that siblings of children with ASD participated in fewer extracurricular activities than the control group, limiting the amount of hobbies the TD siblings were able to enjoy outside of the home. According to the authors, one possible reason for this may be that the majority of the parents' energy is focused on their child with ASD and as a result they do not have the time to facilitate the schedule requirements of taking their TD child to such extracurricular activities. Another possible reason may be due to the financial strain of raising a child with ASD (Barak-Levy et al., 2010). Additionally, the parents of both groups reported on what attributes they would use to describe their TD child. The only significant difference in the characteristics of the children between the two groups found was in relation to their responsibilities. When asked about positive qualities of their TD child, 59% of mothers in the study group talked about how responsible and helpful they were while only 15% of mothers in the control mentioned similar qualities. These findings suggest TD siblings may have greater care-taking burdens or expectations at home than children without a sibling with a disability.

In one of the few qualitative studies with TD siblings, Petalas, Hastings, Nash, Dowey, and Reilly (2009) interviewed 22 children about their experience growing up with a sibling with ASD. Several of the participants reported having to make many concessions in their everyday life to accommodate their siblings. Some of these concessions included having to take care of their sibling with ASD regardless if the TD child was the older sibling or not, conceding attention from their parents, and having limited interactions with people outside of their immediate family. The participants also spoke of not being able to go to sleep until late because of their siblings' disruptive behaviors and having their parents put a lock on their door so that they could keep their siblings out when they needed a break. The TD siblings also frequently mentioned the impact of their sibling's verbally and physically aggressive behaviors on how comfortable and safe they felt in their own home. Other common experiences included feeling angry or embarrassed by other people's ignorance about their sibling's diagnosis and behaviors, the desire for things to be different with their sibling, and the lack of support the siblings felt they had. Even withstanding these difficulties, the majority of the participants reported feeling a sense of appreciation and acceptance toward their sibling with ASD.

As demonstrated above, a review of the literature shows differing opinions on the extent to which having a sibling with ASD affects their TD brother or sister. Some research has shown that siblings of children with ASD have a higher likelihood of experiencing distressing emotions and exhibiting behavioral difficulties (Petalas et al., 2012; Ross & Cuskelly, 2006) and that those emotional problems endure over time (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009). Other findings suggest TD siblings also have positive experiences and adjust well (Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2012; Hastings, 2007).

Positive Effects

Some studies have found having a sibling with ASD does not negatively impact TD siblings (Dempsey et al., 2012; Macks & Reeve, 2007). Attempting to resolve the conflicting results of the impact of children with ASD on TD siblings by conducting a large sample study, Dempsey and colleagues (2012) analyzed parent and teacher reports for 486 TD siblings to see if they showed signs of emotional or behavioral maladjustment. For each participant, both parents and teachers completed assessments regarding the participant's adjustment by asking questions about their emotional, social, and behavioral functioning. An examination of the results found TD siblings' scores to be within the average range for behavioral and emotional functioning compared to a normative sample. These results indicated that TD siblings might not be more likely to be maladjusted than children without a sibling with ASD.

In a similar study of 75 TD siblings of children with ASD, Macks and Reeve (2007) found that the TD siblings had a higher rate of self-concept than siblings of children without a disability. The TD siblings in the study reported having a more positive outlook on their behavior, school performance, anxiety, and intelligence than siblings of TD children. The researchers attribute some of these perceptions to the fact that it would be natural for the TD children to compare themselves to their sibling with ASD and, as a result, view their own behaviors as more favorable. Another explanation may be that siblings of children with ASD have been found to be more mature than siblings of children without a disability (Macks & Reeve, 2007). Taking this into consideration, it is possible that the TD siblings scored higher on the self-concept scales due to their overall maturity. An unexpected finding of the study was that while the overall conclusion was that the TD siblings faired well, as the demographic risk factors for their families increased, such as with the families with lower socioeconomic statuses, the unfavorable psychological impacts increased as well.

Adverse Effects

Contrary to the research that found TD siblings had mostly positive experiences living with their sibling with ASD, there have also been several studies that suggest the siblings are often negatively impacted (Hastings, 2003; Meyer et al., 2011; Rivers & Stoneman, 2008). One such example is a study completed by Hastings (2003). The researcher compared 22 TD siblings of children with ASD to a normative sample of children without a sibling with ASD. The results showed that the siblings of children with ASD had fewer prosocial behaviors, greater peer issues, and more behavior problems, such as emotional problems and hyperactivity, than the normative sample.

In a similar study, 70 mothers who had a child with ASD and a TD child were recruited to participate in a study through a national ASD research database (Meyer et al., 2011). The mothers were asked to complete surveys about the behavior exhibited by their child with ASD and the behavioral strengths and weaknesses of their TD child. Compared to a normative sample, TD siblings showed higher levels of adjustment problems, including higher rates of conduct problems, inattention, difficulties in their peer relationships, and deficits in their prosocial behavior. Moreover, TD children whose sibling with ASD had higher rates of maladaptive behaviors were even more at risk for showing difficulties in these areas of adjustment.

In yet another study, Rivers and Stoneman (2008) had 50 parent and sibling triads complete questionnaires about their family functioning. The child with ASD and the TD sibling were found to have different expectations for their behavior, usually favoring the child with ASD. Results showed that most TD children were unhappy with the amount of attention they got from their parents compared to their siblings with ASD. The authors found a greater amount of differential parenting in the families where the child with ASD had a temperament that was considered to be challenging. Additionally, as the TD sibling's dissatisfaction with the differential parenting increased, the quality of their relationship with their brother or sister decreased.

Impact of Aggression on the TD Sibling

This section will outline the impact physical aggression has on the TD sibling's life. First, the amount of adaptations the TD sibling must endure is discussed including ways the sibling learns to stay safe and the toll taken by living in anticipation of the next aggressive tantrum. Next, this section will explain the parent's perspective of adjustments TD children must make to their daily lives due to their sibling's aggression. Then this section will outline the impact of the aggression from the TD sibling's perspective. In particular, coping strategies TD siblings use and thoughts of fear and anxiousness will be discussed. Finally, the research showing a connection between problem behaviors exhibited by the child with ASD and sibling adjustment will be presented.

One theory for the discrepancy in the literature of the extent to which having a child with ASD in the family affects TD siblings may be that the sibling adjustment is tied to particular behaviors the child with ASD exhibits (Petalas et al., 2012). Understandably, living with a child with ASD that displays physically aggressive behaviors on a daily basis could be a very different experience than living with a child whose maladaptive behaviors are purely of a social nature (Harris & Glasberg, 2012).

Children who have a sibling with ASD are often required to take on more caretaking roles. When the caretaking demands become too extensive for the TD sibling to handle, they are likely to become more withdrawn (Siegel & Silverstein, 2001). The risk of a TD sibling becoming withdrawn is significantly higher when the child with ASD exhibits physically aggressive behaviors towards their sibling. This physical aggression can make the TD sibling wary of the child with ASD over time and the fact that the TD sibling is not able to respond to the aggression through either retaliation or negotiation can compound this frustration (Siegel & Silverstein, 2001).

Unfortunately, it is a common and appropriate reaction for TD siblings to be fearful of their aggressive sibling with ASD. Safety plans are often created for the TD sibling to follow in order to help alleviate the uncertainty of what to do in those stressful situations. Typically developing siblings are taught to notice early signs that their brother or sister is escalating in order to know when to implement their safety plan. These safety plans can range from quickly removing themselves from the situation to preparing to assist in a deescalation or restraint procedure (Harris & Glasberg, 2012).

While it can be theorized that growing up with this sort of vigilance and anticipation of potential aggression could have a significant impact on a child's life, the implications for the TD sibling has yet to be thoroughly researched (Mascha & Boucher, 2006). Although few studies were found that were specifically aimed at examining the impact of aggression, it has been noted as a reoccurring theme mentioned by both parents and TD siblings in previous qualitative studies. Research has discussed the parent's perspective of how they believe their child with ASD's aggressive behavior has impacted the TD sibling (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Siegel & Silverstein, 2001), how the aggressive behaviors have impacted the TD sibling from their own perspective (Mascha & Boucher, 2006; Ross & Cuskelly, 2006), and the correlation between the extent of aggressive behaviors exhibited by the child with ASD and the maladjustment of the TD sibling (Hastings, 2007; Orsmond, Kuo, & Seltzer, 2009).

Parent's Perspective

Although much of the parent's attention is focused on their child with ASD, they have been shown to be keenly aware that their TD child's life is greatly impacted as well. A recent study by Hodgetts and colleagues (2013) interviewed 15 primary caregivers of children with ASD about their perceptions of the extent their child's behaviors impacts the rest of their family. The researchers found that parents reported themes of the entire family experiencing social isolation, exhaustion and the parents themselves feeling concern for the sibling's safety as a direct affect of the ASD child's aggression. Of the parents who reported aggression toward the sibling, all described it as the most difficult part of parenting their child with ASD. They stated the need to rearrange aspects of their family life to accommodate the aggressive behavior to the point of having to consider not having the child with ASD live with them anymore for the sake of the TD sibling's safety (Hodgetts et al., 2013). Examples of the necessary accommodations were required from the parents to keep the sibling safe included contemplating moving the child with ASD to a locked facility and eating meals separately to assure the siblings were never in the same room together. Additionally, parents reported sleeping in shifts in case the child with

ASD woke up in the middle of the night to ensure the child with ASD did not harm the TD child (Hodgetts et al., 2013).

In a study of 166 sibling pairs, Petalas and colleagues (2012) examined what factors predicted TD sibling psychological functioning. Having the parents report on the relationship between the child with ASD and their TD sibling and the behaviors that the child with ASD exhibited, the researchers found that increased problem behaviors exhibited by the sibling with ASD were a predictor of sibling conflict and rivalry. Additionally, problem behaviors, such as physical aggression, were also found to be associated with an increase in problem behaviors in the TD siblings, such as emotional and conduct problems.

Sibling's Perspective

Research has also inquired about how TD siblings would describe the experience of growing up with a brother or sister with ASD in their own words. A study conducted by Ross and Cuskelly (2006) examined the coping strategies used by 25 TD siblings of children with ASD as well as examined which behaviors the siblings perceived to be most problematic. Consistent with other research (Angell et al., 2012), the researchers found that physical aggression exhibited by their sibling with ASD was the top cited concern among TD siblings. Specifically, when asked to identify a problem they had with their sibling, 52% of the participants mentioned aggression first before talking about any other type of interaction. In an effort to cope with this aggressive behavior, the most commonly used coping strategies by TD siblings were wishful thinking and attempting to emotionally regulate themselves. However, many of the TD children reported these coping strategies to not be effective and the most commonly reported emotional reaction to sibling aggression was anger (Ross & Cuskelly, 2006).

In a similar study, Mascha and Boucher (2006) asked 14 TD siblings about their perception of growing up with a sibling with ASD. When asked to identify something challenging about living with their sibling, the most frequent response, mentioned by 86% of the participants, was dealing with aggressive behaviors. Interestingly, while 100% of participants were able to describe something negative about their sibling, 29% were not able to describe anything positive about having a sibling with ASD (Mascha & Boucher, 2006).

Benderix and Sivberg (2007) also interviewed 14 TD siblings of children with ASD who were categorized as having moderate to severe mental retardation. Each of the children with ASD was in the process of being moved into a group home due to the severity of their behaviors exhibited at home, including violent behaviors towards their siblings. Some of the themes that emerged from the interviews included feeling a sense of responsibility for their sibling with ASD, a negative impact on their relationships with friends, and hoping that the group home would provide some relief for their family. An additional major theme revealed in the conversations with TD siblings was the impact of aggression. The researchers found that physically aggressive behavior displayed by the child with ASD made the siblings feel unsafe, frightened, and anxious at home. The TD participants relayed stories of their siblings screaming, kicking them, fighting, smearing feces, abusing the family’s pets, and making loud and persistent sounds. Nearly all of the participants described these experiences as something they did not feel equipped to understand or handle and that they often resorted to locking themselves in their rooms in order to gain some solitude. As a result of these findings, the authors hypothesized that one reason for the inconclusive results in the literature on how well adjusted TD siblings are may be connected to the level of physical aggression exhibited by the children with ASD. Additionally, the researchers contended that there needs to be greater attention paid specifically to the impact of these aggressive behaviors on the sibling experience.

Connection Between Rate of Problem Behaviors and Sibling Adjustment

There is increasing evidence between the amount of problem behaviors exhibited by the child with ASD and the TD sibling's level of psychological adjustment (Hastings, 2007; Hastings & Petalas, 2014; Orsmond et al., 2009). In a study aimed at examining the TD sibling's well-being, Orsmond and colleagues (2009) collected data from 198 adult siblings of children with ASD. The participants were given several questionnaires that measured their psychological well-being, the quality of their sibling relationship, their coping skills, and the extent of problem behaviors exhibited by the sibling with ASD. The results showed that an increase in the problem behaviors exhibited by the child with ASD led to a larger negative impact on their sibling relationship. TD siblings were less willing to engage in public activities with their sibling with ASD and reported fewer family outings than TD siblings whose sibling with ASD exhibited fewer problem behaviors. Additionally, TD siblings whose brother or sister with ASD had a high rate of aggressive behaviors were less likely to choose to spend time with them.

Hastings (2007) conducted a longitudinal study assessing 75 TD siblings of children with developmental disabilities. Thirty-one percent of the children in the study diagnosed with a developmental disability were categorized as severe while the remaining were classified as mild to moderate. Mothers of the sibling pairs were asked to complete questionnaires about the relationship between the TD sibling and the child with a developmental disability at two separate times, once at the onset of the study and once again after two years. Scales were also completed to measure the extent of the TD sibling's problem behavior, such as how often they have temper tantrums, the degree of their emotional problems, and how good their peer relationships were. The study showed that the rate of problem behaviors exhibited by the child with ASD at the beginning of the study was a significant predictor of the level of problem behaviors in the TD sibling two years later.

Similarly, in a study that had siblings self-report on their own behavior problems, Hastings and Petalas (2014) had 94 TD siblings of children with ASD complete questionnaires about their sibling relationship and their own emotional and behavioral adjustment. Although most of the data did not reach clinical significance, TD siblings consistently reported higher levels of behavior problems than a sample from the general population. One of the measures considered to be clinically significant was in regards to the rate of problem behaviors of the child with ASD. Increased levels of maladaptive behaviors in the siblings with ASD were associated with a decreased amount of sibling warmth and closeness and often were associated with higher levels of conflict in the sibling relationship.

Likewise, conducting a longitudinal study of 74 TD siblings of children with ASD, Benson and Karlof (2008) looked at sibling adjustment over several years. The extent of problem behaviors exhibited by the child with ASD and the behavior difficulties TD siblings had were recorded at the onset of the study. Two years later, the researchers completed the same measures. The severity of the child with ASD's symptoms at the time of the original assessment was significantly correlated with the TD siblings overall behavior difficulties two years later.

Limits of the Current Literature

Considering sibling relationships are often the longest standing relationships individuals have in their lifetimes (Green, 2013) and the growing number of people diagnosed with ASD, it is imperative that the experiences of the TD siblings are examined as well. While the research on TD sibling perceptions gives some insight to the impact of aggression, there have been limited studies that examine this experience as a primary focus (Hodgetts et al., 2013).

Green (2013) conducted a systematic review of the literature on siblings of children with ASD. The findings showed that while most quantitative studies found TD siblings adjusted well, qualitative studies often revealed significant emotional challenges. Therefore, Green (2013) suggested the TD siblings may be outwardly coping well and behaving appropriately yet at the same time may be internally experiencing turmoil. Furthermore, hypothesizing that several other factors impact the TD adjustment, Green suggested additional research needs to be conducted on more specific TD sibling populations. With the research yielding results that show physical aggression has an impact on TD siblings that has been largely ignored up until this point, one of those specific sibling populations that is worth looking at are TD siblings of children with ASD that experience physical aggression.

Most of the published research on the TD child's experience of aggression from a sibling with ASD has used parent or teacher report to assess the impact (Benson & Karlof, 2008; Dempsey et al., 2012; Farmer & Aman, 2011; Hastings, 2007; Meyer et al., 2011; Petalas et al., 2012; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009). The limited studies that have asked the siblings directly what their experience is like have resulted in interesting findings that have motivated the field to focus on their experience as a key goal in conducting further studies (Hastings, 2003).

Hastings and Petalas (2014) recently called for further research to be conducted on the impact of the behavior problems exhibited by the child with ASD on the entire family system. Furthermore, Petalas, Hastings, Nash, Dowey, and Reilly (2009) urged researchers to begin to fill this gap in the literature by conducting more qualitative research with the siblings themselves. More specifically, Macks and Reeve (2007) advised more research be done on adult siblings of children with ASD in order to begin to prepare for what is to come with the increased rate of TD siblings who reach adulthood that is sure to be present in our society as a whole.

This study aims to explore the experiences of siblings of children with ASD, the ways physical aggression has impacted their childhood and upbringing, and to assess ways the social work profession can further support this population.

Summary

This literature review described aggression and the impact on the family's lives. The prevalence of aggressive behaviors in children with ASD was discussed, as were the implications of such behaviors on family member's level of stress and well-being. Common treatments for aggression were explained and the role the TD siblings have to play in those treatments were detailed. The accommodations families have to make on a daily basis because of aggressive behaviors were outlined from both the parent's perspective and the sibling's perspective.

This literature review also discussed how TD children often feel overlooked, forgotten, and fearful of their siblings. The connection between the rate of problem behaviors a child with ASD has and the adjustment difficulties for TD siblings was outlined. Finally, the lack of attention in the literature given to this often-ignored population was demonstrated establishing a need for this study.

CHAPTER 3

METHODS

Design

An exploratory, qualitative design was used to examine the experience of growing up with an aggressive sibling with ASD from a TD sibling's adult perspective. Given the exploratory nature of this research, a semi-structured interview approach was used in order to obtain the fullest extent of information possible. Thirteen participants were interviewed to gain a deeper understanding of their unique experience.

Sample Selection and Size

The participants were chosen through a non-probability, purposive, snowball sampling method. The criteria for the participants to be included: (a) over 18 years old and (b) have an aggressive sibling diagnosed with ASD. The researcher used a company, ACES, well known to the researcher to aid in recruiting participants. ACES is a company that provides applied behavior analysis (ABA) therapy for children with ASD and other developmental disabilities. The researcher has been an employee of ACES for the past five years and has a strong relationship with the company. The researcher gave a recruitment flyer (Appendix A) to the Executive Clinical Director of the agency, ACES, to be displayed in the central office where parents who have a TD son or daughter that meets the criteria were able to see it. Furthermore, the researcher attended a supervisor meeting at ACES to offer the opportunity to participate to those that meet the criteria, and to equip the supervisors with the study flyer for them to invite potential participants. Additionally, given the difficulty in acquiring typically developing siblings who met the criteria, the researcher also utilized personal and professional contacts by inviting them to refer potential participants. After participants completed the interview, they were given the opportunity to invite others to participate that meet the criteria as well. Saturation was reached at thirteen participants and thus the sampling size for this qualitative study was thirteen.

Data Collection Procedures

Seven interviews were done face to face in a neutral public setting agreed upon by the researcher and participant. Four of the interviews were conducted over the telephone and two were completed via video chat. Prior to the interviews, the researcher obtained informed consent (Appendix B). The informed consent also sought permission for the interviews to be audiotaped. All participants gave verbal consent and permission to be audiotaped before the interview began.

Instrument

The interviews were conducted in a semi-structured format. Due to the limited research on the topic, the researcher developed an interview guide (Appendix C) for this study. The questions were open ended to allow the participants to fully describe their experiences with their sibling. The first portion of the interview asked the participants to describe in general what their experience was like growing up with a sibling with ASD. For example, one question was “What is one of your earliest memories of understanding or learning he/she had autism?” The next section inquired about their sibling with ASD such as their functioning level and the types of behaviors they exhibited. Next, participants were asked about their responsibilities in caring for their sibling both when they were younger and currently. The participants were then asked how they believed their childhood was impacted by their sibling in the areas of their family life, school life, and personal life. The next portion of the interview asked participants what they experienced as the most challenging and rewarding aspects of growing up with their sibling with ASD. Next, the participants were asked what advice they would give another sibling growing up in the same situation they did. The last open-ended question was in relation to what recommendations they would give social workers and other professionals that assist this population. The last section of the interview covered demographic questions such as participants' ethnicity, education, and age. Given the fact that the researcher developed the interview guide, the reliability and validity are unknown.

Data Analysis

Following each interview, the researcher transcribed the audiotapes verbatim. The data from each participant were then analyzed and coded into themes and categories. Next, the researcher looked at all participant answers and identified similar patterns and the most common responses. Those common responses were then categorized into relevant themes. Quotes from the participants were then selected that best illustrated each theme. Additionally, frequencies and percentages were used to describe the sample's demographic characteristics.

CHAPTER 4

RESULTS

The results from the 13 participants' interviews are outlined in this chapter. First, the demographic characteristics of the participants are presented. Next, the seven categories and twenty-three themes identified through the analysis of the interviews are illustrated. The categories include: dealing with the physical aggression, hypervigilance due to the unpredictability, feeling unequipped, feeling overlooked, strain on the family, rewarding aspects of having a sibling with ASD, and recommendations.

Demographics

The demographic characteristics of the 13 participants are outlined in Table 1. The participant sample consisted of five males (38%) and eight females (62%). The participants' ages ranged from 18 to 37 years with a mean age of 23 years. Six (46%) participants' parents were divorced, three (23%) of which divorced only after the children were grown, and a little over half (54%, n = 7) of the respondents' parents were still together. Three (23%) of the participants had not received a high school diploma. One (8%) of the participants had received a high school diploma but had not done any post high school education. Six (46%) had completed some college and three participants (23%) had received a college degree. The ethnic characteristics of the participants were Caucasian (54%, n = 7), Pacific Islander (31%, n = 4), Asian (8%, n = 1), and Hispanic (8%, n = 1).

TABLE 1. Participant Demographics (*N* = 13)

Characteristics	*f*	%
Gender		
Female	8	62%
Male	5	38%
Age		
18-20	5	38%
21-25	5	38%
26-37	3	23%
Parent's Relationship		
Still Married	7	54%
Divorced Young (under 18)	3	23%
Divorced Older (over 18)	3	23%
Education		
No High School Diploma	3	23%
No College	1	8%
Some College	6	46%
College Degree	3	23%
Ethnicity		
Caucasian	7	54%
Pacific Islander	4	31%
Asian	1	8%
Hispanic	1	8%

Dealing with Physical Aggression

All participants that were interviewed for the current study had a sibling with ASD that had physically aggressive behaviors. Each participant shared specific stories about their brother or sister's aggression and the impact it had on their childhood. These stories would come up at various parts of the interviews. For instance, the participants would mention aggression when asked: about their childhood in general, about their sibling with ASD, how they believed their life was impacted by having a sibling with ASD, and what the most challenging thing was of growing up with their brother or sister. The extent of the aggression ranged in both duration and intensity. The common themes in this category were describing the characteristics of the aggression, being fearful of their sibling's physical aggression, feeling apprehensive about taking their sibling out in public, and developing strategies to deal with the aggression.

Characteristics of the Aggression

In analyzing the 13 participant interviews, it became clear that growing up around physical aggression had made a significant impression on the TD siblings' lives. While the physical aggression characteristics varied from participant to participant, there were three dominant themes that emerged from the analysis. Those themes included describing the aggressive tantrums as relentless attacks, as scattered events, and as having lasting effects on the TD siblings.

Seven (54%) of the participants described the aggressive tantrums as an attack that was relentless in its intensity and duration. The following quote illustrates the attack behavior one child with ASD exhibited:

> [His] tantrums are like a really angry gorilla. You accidently let the gorilla out of the cage and the only way you can put the gorilla back in the cage is if you tranquilize it or let it keep going until it runs out of energy. [He] is like a gorilla. Once he's upset, he's upset. You can never predict when he is going to calm down… once he's had it and he's out of his cage its like the gorilla is just loose on everybody.

Another participant stated the behavior would be like an attack in the middle of the night at times:

> He would get agitated in the middle of the night and get up out of his bed and come into one of our bedrooms and just start attacking us while we were sleeping. It was scary. Yeah, it was not fun.

Two participants described how the aggressive tantrums would carry on for extended periods of time as illustrated in the following quotes:

> It was so bad. I mean every day he would have someone's hair in his hands. Or someone would be calling out for someone else to rip [him] off of them because he was biting or had your hair, or he was scratching. And that sucked a lot. You would just sit there and he would just come over and pull your hair for no reason. And he didn't just pull it. He would latch on and pull for several minutes.
>
> When he would start to attack he would just go after whoever was present so we would all just try to find some room that we could lock ourselves in. My brother would start pacing the house—it was like being in a horror film. You would hear the foot steps moving around the house, and then the banging on the door, and him trying to get in.

The other six (46%) participants explained that the aggression would happen in shorter bursts. These tantrums occurred in scattered events and were not as relentless in nature. One participant described the types of aggressive behaviors her sister would exhibit in the following way: "She would always shove me, or shove me against furniture or maybe even a wall. Either shoving or scratching. She would scratch my arms to get me away." Another described it as: "She would pound the table, throw things off the table, throw things, break things. Push people. Hit people."

Another participant explained what one tantrum looked like when they were out in public:

> One time we were at the mall and we were eating and she threw her whole dinner on the ground and screamed really loud. Everyone turned and looked at her… She kept screaming and she flipped the tables and threw me into a table and everyone was staring and someone called the police and it was a really big disaster.

Occasionally participants told stories about how the physical aggression had lasting effects on their life, either physically or emotionally. One participant's description of an incident that caused serious harm is demonstrated in the following quote:

> There were a few times where he would bite through somewhere where you would start losing a lot of blood really fast… he bit through this nerve on my hand so I still have numbness through this part of my hand.

Another participant described the lasting emotional effects growing up around his severely aggressive sibling has had on his current life with his own children:

> I think that living with [him] gave me a little PTSD to be honest… And because of all of that [aggression] I am scared of my own kids now. I am scared they are going to bite me or pull my hair. You know I don't like my daughter playing around my hair because I always think she is going to pull it. I am still scared even now. Even when I hold my baby I feel like I have to hold them a certain distance because you know they have sharp nails and [my brother with ASD] had sharp nails and you're going to dig your nails into me like he did when he was a little kid.

Fearful of Sibling's Aggression

The majority (85%) of the participants described being fearful of their brother or sister because of their aggressive tantrums. One participant disclosed that he was fearful of getting seriously hurt by his sibling and as a result would have to prepare himself when he had to make his sibling do something he did not want to.

> Back then if you needed to make him do something he didn't want to do like get out of the car you would want to go put some protection on your face and put something on because you were going to get bit, you know there was always a possibility something was going to happen.

Another participant described being fearful of their sibling due to the odd behaviors she would exhibit when she would get upset: "She would do this really loud scream. The loudest scream you ever heard. It was really shocking if you hadn't heard it before. That was scary." An additional participant described this fear as so stressful that his hair turned gray as a result: "It was very stressful. I am pretty sure I was the only 6th grader with gray hair."

Apprehensive in Public

Nine (69%) participants also talked about how the fear of their sibling's aggressive tantrums impacted their comfort level when out in public. There were times when there would be no clear antecedent to the aggressive behaviors, which exacerbated the feeling of discomfort when they would be in a public place. Knowing that their sibling with ASD could tantrum at any time, regardless of where they were, created a sense of unease and tension for the TD siblings.

One participant described how his sibling would begin to tantrum regardless of where he was. In order to prevent innocent bystanders from becoming involved the participant's family would have to "take the beating" themselves.

> It didn't matter. We could be at a restaurant. We could be at a park. We could be in the car. We could be at a store. You know, no clear antecedent ever. A switch would flip in his head and he would go into rage mode…He would primarily target us. Usually what we do is we create a human barricade around him to keep him from lashing out against anyone else. We would just take the beating ourselves.

Another participant talked about being uneasy about being with his sibling in public that he would want to avoid it when possible:

> I would not run the risk of taking him out and him throwing a tantrum and having him run off and attack someone else. And that someone else not knowing he has a disability and then hurting him. I wanted to avoid it.

One participant described the unease of being in public because of the way people would watch when their sibling was having an aggressive tantrum:

> It was really scary. I would just want [the tantrum] to end so no one would watch us anymore. Everyone [else that was at the public place] would look at me and watch to see if I had it under control.

There were times when the child with ASD would become so aggressive in public that the tantrum would be too much for the family to handle on their own, adding to the sense of discomfort. The following quote describes such behaviors: "We were at a [restaurant] and he got really aggressive and we had to call for help and it actually took 4 firemen to take him down. It was pretty intense."

In a related comment the following participant's quote illustrates the anxious, apprehensive feeling that accompanied their sibling's behaviors when out in public:

> When we would be out and something would happen I would just want to be home. I knew that if we were at home we could handle it better. I would just want to get back home as soon as possible.

Strategies Developed

In order to deal with these aggressive behaviors, the TD siblings developed several strategies of their own. Ten (77%) participants credited the fear and intensity of the aggressive tantrums for teaching them to become resourceful and to create tactics to aid them in those particular situations.

One of the strategies talked about was becoming skilled at recognizing when to leave the situation and creating techniques to get out of the way quickly. One participant explained how she would use the tactic of escaping by leaving the room when a tantrum started in order to reduce her fear: "When I was younger I would be very scared. I sometimes would go hide in the other room until it was over because I was scared she was going to hurt me."

In another example one participant had to get creative in order to get away from his sibling when the aggression would begin:

> His tantrums scared the crap out of me… I didn't get bit as much because I would jump over things and duck dive to get out of the way. But it was really scary. It was bad… There was always anticipation that it was going to start but most of the time I just didn't want to be around him. I feel so bad about that now. Because I basically ignored him.

Hypervigilance Due to Unpredictability

Many of the participants described having to be cautious and aware of the situation around their sibling. Since their safety often relied on being able to get out of harms way, they did not have the luxury of going about their daily life without regard to how their brother or sister with ASD was feeling or acting. This hypervigilance created a feeling of fearful anticipation, having to constantly scan the environment to assure it was safe, and having to pay attention for those unsuspecting people that encountered their sibling.

Fearful Anticipation

Eleven (85%) of the TD siblings interviewed expressed how they felt like they did not know when the aggression would begin and as a result felt like they were living in fearful anticipation. While many reported becoming better at reading the subtle signs that their sibling with ASD was beginning to escalate as they got older, a reoccurring theme in the interviews was that for most of their childhood the tantrums were unpredictable.

One participant noted that the unpredictability of the behaviors and stress of having to always be anticipating the aggression was the most challenging part of their sibling with ASD:

> The most challenging for me was just the unpredictability. A lot of days would be fine but you would just never know. A lot of times outings would be super stressful because you would never know at what point today is he just going to say enough and go off…That was the hardest for me. Anticipating that aggression. I was never fully relaxed…Just not knowing when or if it was going to happen was the most stressful for me.

The following quote demonstrates how the aggression was sudden and unexpected:

> We didn't know the signs he was about to flip so we couldn't predict when he was going to attack. It came out of nowhere. I really didn't know what to do. It was like a surprise attack type of thing.

Another participant explained the things he would do in anticipation of the aggression. He describes how he would position himself in a way that would let him get away easily in case a tantrum started in the following quote:

> It was just really frustrating. I hated sitting in the living room and just always trying to anticipate when [he] was going to attack me. For a while I didn't want to be around [him] at all. You keep your distance. And put things in between you. So you know just in case he was going to attack me it was like, oh you have to climb over this thing to get to me. So by the time you climb over this I had a chance to get away—I'd be long gone. It was frustrating and annoying and it was painful for me to do that to him…I would try to avoid [the aggression] any which way I could.

When asked how it felt to be around their sibling with ASD, one participant described the constant stream of questions that would go through his mind. The following quote illustrates the experience of having to continuously assess the situation and the fear that anticipation caused:

> Living in that constant fear of like, oh shit—am I going to get bit? I am going to get my hair pulled? Am I going to get scratched? Is my favorite shirt going to get stretched out? Should I not even wear this shirt today? Should I not even wear a shirt at all? But if I don't my skin is going to get hurt because he is just going to grab onto it. So just all of that stuff pretty much added to everything every day. It was scary. Constantly aware of everything that is happening around me. I don't want to deal with that anymore. [He] was so smart. He would figure out all the different ways he could hurt us. He would figure out how to use his aggression to his advantage. He became a master of using his aggression to get what he wants.

One participant talked about the tension that was created by having to live in that anticipation. She describes the feeling of having to always be aware of what was happening around her: "I knew I had to be always aware. There was this extra tension between us…Just always being aware of where she is and where you are."

Scanning the Environment

The participants also talked about having to being hypervigilant about their environment. Eight (62%) participants described having to be aware of what was happening in the physical space around them, whether that was at home or out in public.

One participant described how they had to proactively look around and assess what could be harmful during an aggressive tantrum. This created a sense of having to always second guess everything that she did even when her sibling was calm so that all dangerous objects were out of the way in the event that a tantrum would start.

> We try and hide all the sharp objects and glass…We are always looking around the house to see what he could potentially use as a weapon and move it to high places… You worry a lot. Can I leave this pencil here or will he try and use it? Or even forks. We can't leave those out… You have to second guess everything.

Another TD sibling explained the constant anxiety of having to scan the environment to identify what stimuli could potentially trigger a tantrum:

> There was always anxiety around him. Like you would be at a restaurant and there would be a baby crying… you could see him get really tense… but sometimes you think it's going to be ok but then all the sudden he would just grab something and throw it and it would be like ok, we are over the edge.

One participant described the experience of having to be cautiously attentive to the little things in their environment, such as what their sibling with ASD was talking about. At times, it was difficult to decipher the mood their sibling was in so the family had to resort to paying close attention to what he was saying in order to identify when a tantrum may be imminent.

> We were always on edge. We would always have to be trying to listen to what he was saying to himself because that would dictate what mood he was in… if he is talking about Shrek you know he's in a good mood. If he starts talking about something else you have to be careful.

Concern for Others

Due to the fact that other people were not used to their sibling's unpredictable behaviors, the TD siblings took on the responsibility of being aware for them. Seven (54%) of the participants talked about the stress of having to be extra attentive when other people were present so that they could make sure their sibling did not attack them. Not only would the TD sibling have to be hypervigilant around their brother or sister for their own safety but they also would have to watch out for others when they were around their sibling who did not have the same kind of awareness of the situation. The following quotes illustrate this theme:

> Having people over, you had to make sure everyone steered clear of [him] because of his aggression. You know, you're talking to them but then you have to turn around every 3 seconds to make sure [he] is in the same spot and not closer. You know, is he ok? Because if he's not ok, he's going to flip.
>
> I did have friends come over but not as often as I went to friends houses and I think it was because I knew there was a potential that they might see a tantrum or see something that was out of the ordinary for them. It stressed me out a little bit to be honest.

Unequipped

When talking about the types of behaviors their siblings exhibited, all 13 participants described feeling unequipped to handle the aggression at some point or another. The most common ways the TD siblings experienced uncertainty when it came to their brother or sister's behaviors were not knowing how to handle the aggression, being at a loss for what could be done to help the situation, and feeling helpless.

Not Knowing How to Handle Aggression

The participants expressed how they did not know what to do when their sibling became aggressive. The types of tantrums these TD children would have to deal with on a regular basis were so unconventional in typical families that the participants reported a sense of utter confusion and not having the knowledge base to draw from. As a result, many of those interviewed expressed a sense of not knowing what to do, such as the following participant: "When she would be aggressive and I would have to deal with it—I would have no idea how." Another participant spoke about looking back at his childhood and realizing that his family was not equipped to handle the aggression as evidenced by noticing the things that they had not established, such as a safety plan.

> He would target whoever was easiest at the moment. We didn't have a safety plan or anything. We would just kind of wing it as things happened. And in

> hindsight its like, wow it would've been cool to know some Pro-ACT [restraint training] or something like that that we could've used in the home. Or some plan that was like, ok if this happens we are going to go to this room until he calmed down, but no, we just kinda made do.

Other participants described the sensation of becoming frozen out of fear of not knowing what to do. The following describes one sibling's experience: "It was scary. It was very very scary. So many things would be running through my mind for safety... when it happens I just blank out because I am scared. I don't know what to do."

Being at a Loss for How to Help

Seven (54%) siblings talked about wanting to help their brother or sister in some way but felt like they did not know what they could do to make the situation better. The TD siblings spoke of being unclear about why the tantrum was happening in the first place and thus did not know what could be done to help. One participant said:

> We would be out at the park somewhere and she would just start out of nowhere and I wouldn't know what to do because I didn't know what was causing it or what would help her feel better. It was very unpredictable.

Another participant reported trying techniques that she had seen other members of her family use but those techniques did not work for her. As a result of this she described feeling like she did not know how to help her sibling when the tantrum would begin.

> It's like it wouldn't end until it ran its course so I would try techniques that I saw my mom using but it wouldn't work and I wouldn't know what to do… I feel like I still don't know what to do. I still get scared…There was nothing I could do to make it stop.

Helpless

Often times the uncertainty and unpredictability of the aggression were so great that many participants described it as feeling "helpless". Six (46%) of those siblings interviewed discussed the vulnerable emotion that accompanied this helpless feeling. The following quotes describe how the stress of feeling powerless created a hesitation and lack of confidence:

> I would try to be brave and try to be strong but a lot of times it wouldn't help her stop so I would just feel so helpless….. I wouldn't be able to stop the tantrum from happening so I would just let it run its course. I would have no idea what to do.
>
> I just felt helpless for a long time. I mean we didn't know what to do. Me and [my other typical brother] did not know what to do. And he's going to get anyone that is in his way…And it was really really hard for us to cope with that.

Feeling Overlooked

The amount of attention and time that was required to deal with their sibling's behaviors associated with ASD took a toll on the TD siblings. The participants reported that many aspects of the family's daily life had to be adjusted to accommodate the child with ASD. By having to make these adjustments, the TD siblings were left with a feeling of being overlooked. Some common themes that came up in the interviews were the TD sibling feeling less important than their sibling with ASD and feeling isolated from the rest of their family. Additionally, there were statements of wishing their brother or sister was typical, attributing the ASD for the reason they felt overlooked.

Feeling Less Important

Several of the sibling participants (69%, *n* = 9) talked about how they felt less important than their brother or sister with ASD in some way. These experiences included feeling pushed aside by their parents and being frustrated with the different behavior expectations they had from their siblings. The following quote illustrates one particiapnts experience of feeling "pushed aside":

> I was kinda pushed aside. Not so much when they were little and they didn't need that much attention. They would try to spend as much time with us as they could. But then once they started to get older and the autism progressed—once the autism felt like it took over the whole thing—me and [my typical brother] were pushed off. It was hard for them to divide the time up between us all so for me like it felt like, ok just go do your own thing. I had to get from point A to point B by myself. It was like, what the hell am I doing?

The following quote is from a participant who felt frustrated that her sibling with ASD's schedule felt more important than her own:

> I learned that it was all about his schedule. And I was on his schedule. I ate when he ate. I ate what he ate. If we had to leave because he was getting frustrated we had to leave. It was all on his time. I would get really frustrated with that.

Another participant described feeling neglected and that like he had to make it on his own because his parents were so focused on his sibling with ASD's needs. This feeling that he was not as important has lasting effects on his relationship with his mother as described in the following quote:

> It felt like I had to make it on my own… it was like, ok if you are going to neglect me then I am going to neglect you back. At times I didn't think they cared about me…There was so much stuff that went on between us and our parents. I was ripped away from my parents. I mean I love my mom but I don't think I can ever forgive her for what she put me through.

Some participants reported the family outings were dictated by whether or not the child with ASD could handle the setting:

> Everything that we did as a family revolved around if he could handle the environment. The noise. Wherever we were going if it was going to be too crowded. So it was just being very flexible all the time with someone else's needs who was much more important than ours.

> Pretty much every single place that we went to we had to make sure we could get in right away and that we could sit next to the window. And we had to make sure everybody had looked at the menu and knows what they want to order so that

> when we sat down, in case he had a behavior, we were ready to go. We always planned ahead. We had to pick places that weren't dark… We just catered to him. Or sometimes we would be places and my mom would have to leave with him and they would come back for us.

One participant describes how it felt unfair that his parents had different behavior expectations for him than they did for his sibling with ASD. The following quote describes how the participant felt that his brother was more important when they were younger because his parents seemed to ignore the sibling's behavior while punishing the participant for his reaction to that behavior:

> And when we were young we would get upset [when he would become aggressive], you know, like 'What are you doing man? Get away from me.' And then we would get in trouble for talking like that. And we just thought that was really unfair. Like how am I going to get bit and have my hair pulled and scratched and then I am going to be the one who is getting in trouble because I am not just letting it happen to me? That was really stressful. I mean [my brother] back then was really scary.

Isolated

Nine (69%) participants felt like they had to handle the emotional effects of the aggressive tantrums on their own. They reported an isolating feeling due to feeling like they could not talk to anyone else about what they had experienced, including their own family members.

> One time after she had a big tantrum when we were out in public with just me and her…It was like no one understood. I was telling [my parents] how hard it was and I was crying and stuff they were like 'Why are you being such a baby about it?'… No one really acknowledged that it was hard or that was a big deal… It was isolating.

One participant stated that his family members dealt with the stress of the aggressive outbursts by not talking about it and relating to each other like "everything was fine":

> We just sort of dealt with it. It was just an understanding that we were just going to go through this and deal with it when it happens and other than that we wouldn't really talk about it. When I look at it in hindsight it's like, wow we really should've talked about it more than we did. And prepared for things more than we did. I feel like we all just sort of shut down almost and go through this mode of just dealing with it and then just come out and pretend like everything was fine.

Similarly, the following quote illustrates how one participant felt rewarded by appearing to be able to handle the emotions on her own and as a result continued to keep up that façade:

> I felt like I had to constantly present a very calm and mature self to everyone because I didn't want them to worry about me. But at the same time I did have these emotions that I wasn't expressing… And I would get a lot of praise for being a good sister so I felt like I had to live up to that image.

Wishing Their Sibling Was Typical

In regards to the feeling of being overlooked, several (62%, $n = 8$) participants wondered if they would have felt that way if their sibling was typically developed. From the child's perspective, it is understandable to blame the ASD for their feeling of being overlooked and thus wanting the diagnosis to go away. Many stated that at times they had wished their brother or sister did not have ASD, especially when they were younger, and wondered how their life would have been different. One participant said: "A lot of you know, why is my brother not like other kids? And why cant my brother play baseball with me in the yard like other peoples brothers do?"

The following quotes are some other examples that help illustrate the TD sibling's thought process and reasoning for why they would wish their brother or sister did not have ASD:

> I didn't have the typical sibling relationship. That's one thing I've always wanted… I remember growing up and feeling kinda cheated out of that normal sibling relationship. You know actually close siblings, I never had that. Instead of having a sibling relationship I had a caretaker relationship.
>
> I would think a lot how our lives would be different if he was typical. And I remember, especially when I was younger, I would look how a normal brother would be and how they would do the things I would envision normal little brothers doing together.

Strain on the Family

When asked how having a sibling with ASD had impacted his or her family, every participant noticed the strain the aggressive behaviors caused on the family in one way or another. The most evident areas of strain on the family unit were on the parents' relationships, the family needing to make extreme modifications to their lives in order to accommodate the behaviors, and the home feeling like home was a public place as a result of the in-home treatment.

Parents' Marriage

One of the ways the participants noticed the strain on his/her family was in his/her parents' relationships. Several of those interviewed reported seeing the negative effects on their parents' marriage and many (46%, $n = 6$) ended in divorce. Half (50%, $n = 3$) of the participant's parents that got divorced did so when the siblings were young children and the other half (50%, $n = 3$) got divorced when their children were grown and out of the house. The participants whose parents remained married until their children were older reportedly did so because of the financial and emotional stress of caring for the child with ASD was too much to handle separately. The participants who spoke of their parents' relationship stress mentioned how they believed the stress of the aggressive behaviors "tore [their] parents apart" and that they could see the divorce coming before it happened. One participant stated: "I know it was hard for my parents. I could see them fighting. I could see them sad. I think for some reason they had guilt like they had something to do with it. Other participants mentioned similar observations:

> [My parents] are separated now. I think they stayed together more because of helping the kids and financially it was difficult… The behavior was a stressor. I was wondering my whole childhood when they were going to get a divorce so I could definitely see that coming.
>
> Right after the bad behaviors happened my step dad moved out. I think he wanted to leave that home and start a new life, start over and move, and my mom just didn't. So that's when they separated… It really tore my parents apart.
>
> Well they got divorced. And I think my brother was a big component to that happening. My mom was more freaked out by it and my dad was kinda just more 'It's ok, we will find a way to deal with it.' And then my mom would be like, 'How can you say this is ok? This is not ok. This is going to be going on for the rest of his life.' And it seems like that happens a lot. I know divorce rates are really high. And I can see why.

Extreme Measures Families Took

Other siblings (46%, *n* = 6) talked about the extremes their family had to take in order to deal with the behaviors. For many of the families, the level of disruptive behaviors in their homes required substantial accommodations.

One participant recalls being sent away to live with family for a year so that his parents could focus on the sibling with ASD. Due to the fact that his sibling's behavior treatment required the constant attention of their parents, the best option his parents saw was to have the TD children move away for a time until they got the aggression somewhat under control.

> We went back to Guam at one point and lived with our family out there. That was hard. We did not want to leave. We were forced to get on a plane and leave. It was so my mom and dad could focus more on [my brother with ASD]…We were confused as to why we were going though. I didn't understand that. We came home from school one day and it was like, 'Here are your plane tickets.' I didn't even get to say goodbye to nobody.

Another participant explained how her family stopped certain family traditions for a portion of time due to the disappointment it would create in her parents:

> When [my brother] was around five we stopped doing Christmas. My parents didn't want to do the whole thing because he didn't get it… We would just to Mexico… I think its because he was so young and they were used to their other normal kids doing this normal Christmas thing and it was like a constant disappointment. You know like, he doesn't get it, he doesn't get it.

The following quote outlines some of the extreme measures one family had to take in order to make their home safe due to the child with ASD's aggressive behaviors:

> Anywhere from throwing his TV out the window to breaking the shower glass door, all the frames in the house, dressers were always knocked over. So everything in his room is completely bolted down, mounted to the wall. His TV has a plastic panel over it. All the doors were combination locks in and out so he couldn't run away.

Home as a Public Space

Another common strain on the family was the effects of having an applied behavior analysis (ABA) therapist in the home nearly every day. This caused some participants to feel like they did not have the privacy a home usually offers. Eight (62%) of the participants made some mention of the negative effects ABA had on them personally growing up. One participant put it simply by saying: “Having people in our home every day. That was annoying.”

The following quotes further explains participants reactions to having people in their home to provide therapy for their sibling with ASD:

> We had ABA services in the home since she was like two. We always had a stream of, I mean they weren’t strangers, but the home always felt more like a public place I felt like. We had people coming in constantly. And I didn’t always like that. It felt like we didn’t have a lot of privacy. And my mom was always very concerned about having a clean house so there was a lot of extra cleaning involved.
>
> I remember I was always really embarrassed with all the therapists over. I was really shy. I didn’t want them to see me in my house if I was in my pajamas or if I wanted to go eat a snack or something, I didn’t want the therapists to see me so I would just hide in my room. I kept to myself.

Rewarding Aspects of Having a Sibling with ASD

Even with all the challenges the TD siblings described about growing up with a sibling with ASD, they also spoke about rewarding aspects of growing up with their brother or sister. In all of the interviews, the TD siblings mentioned how much they loved their brother or sister with ASD and that they felt like they learned so much by having them as a sibling. The primary traits the TD participants attributed learning from their siblings were patience, compassion, being better prepared for life, and pride for their sibling’s accomplishments.

Patience

Almost all (92%, $n = 12$) of the participants said they felt they had learned a great deal of patience by growing up in the environment that they did. They were required to be flexible with their schedules and preferences in order to accommodate their sibling with ASD. One participant stated: "I've developed way more patience than I think many people. It's prepared me for a lot… it made me more understanding and a better person." Another participant echoed the same attribute: "I have an extraordinary amount of patience. I can see that as a benefit as living with that and dealing with those situations. Now I am not really as fazed by those things as some people might be."

Compassion

Ten (77%) participants talked about feeling like they have learned compassion and empathy towards people due to learning about adversity from a young age. They described themselves as being more emotionally mature than most of their peers and having an understanding of the importance of accepting people despite their differences. The following quotes demonstrate this theme: "I'm more compassionate. I feel like I pretty much empathize with people going through things." Another participant said: "Having [him has] made me appreciate everyone whether they have a disability or not. Because looking at [him] I see life as very valuable. Life is very valuable. Looking at him made me appreciate other people." An additional participant stated:

> I think it made me more emotionally mature at a younger age. I was more understanding of people… you can never know what they are going through internally so I think I was a more emphatic understanding kid than other kids my age.

Better Prepared for Life

Several (69%, *n* = 9) participants stated they felt like they are more equipped to handle the challenges of life because of growing up with a sibling with ASD. The sentiments they described included feeling like they were a better person for having a sibling with ASD. Additionally, because of the hardships of their sibling's aggressive behaviors, they feel more confident that they can make it through other challenges that come their way.

> I feel like it has made me really affectionate towards other people with all different types of disabilities. I feel like I have one step ahead in dealing with life. I just feel smarter and like I can handle anything.

Another participant stated: "I think I have a lot more empathy now. Towards all different kinds of people. And that I can handle anything that comes my way now." A third participant shared a similar attitude: "I can't really put into words how much I've learned from them. They've taught me so much and made me such a better person."

Pride

Another commonly mentioned rewarding aspect of having a sibling with ASD, mentioned by eight (62%) participants, was the pride that they felt seeing their brother or sister making progress and remembering how far they had come. The following quotes illustrate the unusual amount of pride sibling's of children with ASD felt:

One participant speculated if other siblings got to experience the same amount of pride from their relationships and described the sense of joy she gets from seeing her sister improving: "When I see her happy and I see her improving it makes me so happy. I don't know if other people get that sense of pride from their relationships with their brothers and sisters." Similarly, another participant mentioned a similar sentiment: "Watching all the progress she makes and all the things that she is so good at and her success in school. It makes me so proud."

One participant spoke about the pride he felt in direct relation to seeing his sibling make improvements in the area of his aggressive behaviors: "At one point [his] aggression was at 100%. And it went down to like 75%. And now it's maybe like 25%. It's amazing to see how far he has come. I'm so proud of him."

Recommendations

When the participants were asked what additional supports they wish they had growing up, all of them were able to easily identify what they felt could have been done differently to help them. The most commonly mentioned theme that emerged during the interviews was the participants wishing they had more formal education both about ASD in general and about how to properly react to physcially aggressive behaviors. Other themes were desiring to meet and connect with other siblings of children with ASD and a belief that either individual or family counseling would have been helpful when they were growing up.

Education

All participants reported wishing they were taught how to deal with their sibling's aggressive behaviors better. Seven of the eight (88%) of the participants that mentioned ABA therapy in their home stated that they felt like they enjoyed learning from the therapist and that they were smarter for having the therapists around. One participant explained it as: "The ABA in the home was fun. It was a fun learning experience. I would take what I learned from them and I use it in my daily life." At the same time, there seems to have been a disconnect between the limited teaching the TD siblings got and that translating to the participants feeling confident in their knowledge of what to do. The same participant stated formal education from experts in the field would have been helpful: "I wish the therapists would've told me specifically what I could've done to help [during those behaviors]."

The participants repeatedly mentioned these mixed feelings of enjoying learning during ABA and still feeling like they were unprepared. The following quote is from a participant who talked about wishing they had been taught how to deal with the aggressive behaviors and desiring a plan of action to help ease some of the uncertainty surrounding the chaotic tantrums:

> I definitely didn't know how to deal with her behaviors. At the beginning I would just want to fight back… It would've been nice to be taught how to handle those behaviors…an action plan of what we could do when she had her meltdowns.

Another participant stated a specific plan for what the family was going to do during the tantrum for each setting they may encounter would have been helpful:

> I guess just having a plan for when those thing happen would've taken the stress out of some of those situations. Instead of just pretending like everything was going to be ok. You know like, oh well if something happens we will just deal with it. I do think that's important for families that are starting to see those aggressive behaviors to get together and talk and come up with those plans. Like ok if this happens at home we will go over here and do this and if this happens while we are out and about this is how we will handle it. Just to help with some of that anxiety.

Another area of education that was lacking from the siblings perspective was non-existent teaching on how to play and interact with their brother or sister with ASD. Due to the fact that children with ASD often do not play in the same way that TD children do, a few of those interviewed reported not knowing how to get their sibling to play with them. One participant described this by saying: "I wish I had someone teach me how to play with my sibling. Having that sort of education." This is a simple aspect of sibling relationships that children with only TD siblings take for granted.

Additionally, several participants (54%, $n = 7$) reported desiring explicit teaching of what ASD was in order to help them understand their sibling better and assist them in explaining the disorder to their friends. The following quote explains what one participant went through not having the appropriate language to make sense of the disability as a child:

> I think it would've been cool to have some sort of classes that better explained what autism is. It's hard to understand when you were really little. It would've helped to explain it to my friends too. I was just left to my own devices and like, 'Oh yeah well he just doesn't talk and he bites people.' That's the extent to what I knew about him…Some [education] like that in really simple easy to understand language that's geared toward children.

Furthermore, several participants reported having an incorrect idea of what ASD was because no one had told them in a way that they could understand. This resulted in the participants feeling confused about their sibling's diagnosis and, because ASD can manifest so differently from person to person, feeling confused when they saw other children with ASD who seemed very different than their siblings. One participant described this as:

> It got confusing to me because I would meet other kids with autism but they seemed different than my brother. That's when I got confused on what is autism exactly… I just went along with it… I didn't have courage to ask someone about it so that I could actually understand it.

Meeting Other Siblings

The TD siblings described often feeling like their peers could not relate to what they were going through because they did not understand the unique experience of having a sibling with ASD who had aggressive behaviors. As a result of this, ten (78%) participants stated they would have liked to meet other siblings of children with ASD. This desire is described in the following quotes:

> It would've been nice to have a place for like a sibling support group. Just to know that there were other kids like me that were going through these things.

> That also had siblings with autism. That would've been cool…Just recognizing that there are emotional costs to having a sibling with autism.
>
> Recently I went to an Autism Walk and met another sibling there and that was really cool. Meeting other people is a really good idea. Then you know you aren't alone. That other people are dealing with the same things you are dealing with. That helps you better understand your own situation.

Counseling

Nine (69%) participants also reported wishing family and individual counseling was available to them. They stated they felt that family therapy would have been helpful to assist their family in communicating with each other about the challenges that accompany having a child with ASD in their family.

> If there was one thing I wish that I had more of is for my family to go through some kind of family counseling. I think that if we had all sat down together and talked about the things that we were struggling with and who was missing things it would've been a lot easier for our family. It was almost like we just kept going, like robots. And it was like we all forgot to pay attention to what we were feeling… if we were able to all sit down together without any judgment and lay it all out there, I think that would've benefited my family.
>
> If we all went to therapy before it got really bad then we would've all been on the same page. Yeah we would still be stressed out but it wouldn't have gone as far as it did. It wouldn't have gotten as bad in our family as it did. If we all could've just talked it out, you know?

Others said they wish they had personal therapy to be able to work through some of their own difficulties in a safe environment. One participant explained she felt like there was a "grieving process" she had to go through as a sibling when she realized she would never have a "typical" sibling relationship. Her recommendation for counseling was communicated in the following quote: "For siblings I definitely recommend counseling. Especially if they aren't moving past the grieving process you have to go through."

Another participant reported that he had not gone to therapy when he was younger and believes that it would have made a positive impact for him:

> [I wish I went to] therapy. I mean you can have patience but your patience will run out. You need to get in there and talk to somebody about what's going on. You can't just think you can take it all on. You'll snap. You have to go to therapy. To seek help for yourself. If you aren't healthy you can't help anyone else… Leave all your stuff and problems at therapy.

Summary

The most common themes that emerged from the interviews with the 13 participants begin to give insight to the unique experiences of TD siblings who grew up with a brother or sister that had physically aggressive behaviors. The interviews demonstrated the complexities of having a sibling with ASD, described what TD siblings go through on a daily basis, and gave ideas of how to better assist this population in the future.

CHAPTER 5

DISCUSSION

This study explored the experiences of 13 participants who had grown up with a brother or sister with ASD who displayed physically aggressive behaviors. The purpose of the study was to use an adult sibling's perspective to understand the ways the participants felt their sibling has impacted their life and the unique challenges they faced growing up in that environment. Furthermore, the study also examined what recommendations the TD siblings would have for professionals assisting this population to better meet their needs.

Summary of Findings and Comparison with Existing Research

All participants were able to identify ways in which their lives were significantly impacted by having a sibling with ASD. More specifically, the participants of the current study had particularly unique experiences as a result of their sibling's aggressive behaviors. To date, there have been no research studies that this researcher could find that were designed to explicitly explore the TD siblings' experience of aggressive behavior in their brother or sister with ASD. There were, however, several qualitative studies with TD siblings that found physical aggression to be a reoccurring theme (Benderix & Sivberg, 2007; Ross & Cuskelly, 2006; Mascha & Boucher, 2006). Given this fact, the findings of the current study can only be compared to those studies that found aggression to be a significant theme and those studies who interviewed TD siblings about their experiences in general.

The present study found that the majority of TD siblings felt fearful of their brother or sister when they became physically aggressive. The participants often provided detailed narratives of the aggressive tantrums and stated that they made them feel unsafe and anxious. This finding is consistent with the research by Benderix and Sivberg (2007), Mascha and Boucher (2006), and Ross and Cuskelly (2006) that found that TD siblings are often afraid of their brother or sister's aggression.

This study also supported previous studies that found TD siblings do not feel equipped to handle the aggressive tantrums (Benderix & Sivberg, 2007; Ross & Cuskelly, 2006). The participants of the current study all reported similar feelings of uncertainty at some point in their childhood. They would repeatedly mention that they did not know what to do and that they wished someone would have better prepared them to deal with the aggressive behaviors.

Another finding of the present study is the reoccurring themes of TD siblings feeling overlooked, pushed aside, and that their needs were not as important as their sibling's with ASD. Similar themes were identified by Chan and Goh (2014), McCullough and Simon (2011), Moyson and Roeyers (2011), Rivers and Stoneman (2008), and Petalas, Hastings, Nash, Dowey, and Reilly (2009). Given the fact that this theme has been repeatedly illustrated by several studies, this finding substantiates the growing body of research that illustrates the significance of feeling overlooked for TD siblings.

Similar to previous research (Angell et al., 2012; Petalas, Hastings, Nash, Dowey, & Reilly, 2009), the present study found that TD siblings often experience conflicting emotions about their brother or sister with ASD. While the participants in the current study could identify challenging aspects of growing up with their sibling, they could just as easily identify rewards. For example, they spoke about learning patience and compassion from their sibling and believed they were better for having a sibling with ASD and yet they also disclosed wishing their sibling was typical at times. Additionally, they described how proud they were of their sibling's accomplishments and on the other hand that they were occasionally embarrassed due to their siblings' behaviors.

The current study also identified the strain on the family as a reoccurring theme mentioned by the TD siblings. The participants in the current study frequently reported that their daily lives were greatly influenced by their sibling and their behaviors. Some of the most common challenges referenced by the participants were the strain on their parent's relationship, the extremes their families had to take due to the aggressive behaviors, and not having the privacy in their home they desired. Similarly, Lecavalier and colleagues (2006) also found that families with a child with ASD had to rearrange many aspects of their daily life in order to accommodate the child's behaviors.

In contrast to the literature by Mascha and Boucher (2006) that found that several of TD siblings could not describe something positive about having a brother or sister with ASD, the participants of the current study could all readily identify positive aspects to their sibling relationship. When asked to identify the most rewarding thing about growing up with a sibling with ASD, the most common responses included learning patience, empathy, compassion and feeling pride for their sibling's progress. One possible reason for this discrepancy from the aforementioned research may be the age of the participants interviewed. The participants in the study conducted by Mascha and Boucher (2006) were between the ages of 11 and 18 while the participants of the current study were all adults. One feasible explanation is that TD siblings of children with ASD can more easily identify rewards when they are older and thus have more perspective on the situation.

An additional difference between the current findings and previous research is the extent to which the invisibility of ASD impacted the TD siblings. Contrary to the findings of Moyson and Roeyers (2011) that identified the lack of physical attributes associated with ASD as a major reoccurring theme discussed by their participants, only one participant in the present study mentioned this invisibility factor. It is possible that the participants interviewed for the current study did not experience the invisibility explained by Moyson and Roeyers (2011) because their sibling's extreme behaviors made them stand out more than a child with ASD without aggressive tantrums do. Based on the fact that several participants told stories about their sibling having aggressive tantrums in public and the reactions from those around them during the tantrum, it is reasonable to presume they did not feel like their sibling with ASD had this invisibility factor.

Limitations

There are several limitations to the current study. Due to the small sample size, the findings of this study have limited generalizability. Causality cannot be determined given the lack of experimental design. Furthermore, because of the level of subjectivity in qualitative research, the results are only suggestive. Additionally, because the researcher developed the interview guide the reliability and validity are unknown.

Implications for Social Work Practice

The findings of the present study suggest several avenues social workers could take to better assist, support, and advocate for TD siblings of children with ASD who have physically aggressive behaviors. Based on the finding that all 13 participants mentioned feeling unequipped to deal with the aggressive behaviors, it is recommended that formal education is offered to TD siblings of children with ASD who have aggressive behaviors about what to do in those situations. The participants also reported they would have appreciated education about ASD in general in order to better understand it themselves and to feel more confident when they explain it to others. Additionally, a common theme of the current research was the TD siblings recognizing that having formal restraint training and creating a safety plan as a family would have been helpful. With these things in mind, it is also recommended that professionals working with this population whose siblings have extreme aggressive behaviors incorporate this type of education in their interactions with TD siblings.

An additional recommendation based on the current study's findings is to offer support groups for TD siblings. Several of the participants mentioned wishing that they knew other siblings of children with ASD when they were growing up so that they could have a friend that could relate to what they were going through. Based on the finding that TD siblings often feel isolated, linking this population with others that are going through similar challenges would offer an opportunity for the youth to feel connected.

Furthermore, social workers who encounter TD siblings of children with ASD should assess their need and desire for personal or family counseling. The reoccurring theme in the current study of participants reporting that they felt like they did not have a safe place to process the emotional challenges they were faced with warrants attention from counseling professionals.

Implications for Future Research

Given the fact that there is a very limited research base for this population, future research studies would be beneficial in aiming to better understand the unique experiences these siblings have. By acquiring more research on TD siblings whose siblings have aggressive behaviors, service providers would be able to create and offer more appropriate resources.

This researcher recommends quantitative studies that compare the well-being of TD siblings of children with ASD who had aggressive behaviors with the well-being of siblings whose brother or sister did not have aggressive behaviors. With data comparing these related yet notably different populations, the hope would be to provide quantifiable information that points to the significant impact aggression has on TD siblings' well-being. Furthermore, additional qualitative studies that interview TD siblings whose brother or sister with ASD had a wide range of aggressive behaviors would give a more complete picture of which specific behaviors most affect TD sibling well-being. With this information service providers would be able to identify which TD siblings may be at the greatest risk for maladjustment and intervene with the siblings from a young age. Based on the current study, TD siblings believe they would benefit from education, support groups, and counseling services. It is also recommended that program assessments on existing services geared toward TD siblings to evaluate their effectiveness.

In summary, this study offers a more extensive look at the experiences of TD siblings who have a brother or sister with ASD that exhibits aggressive behaviors. Due to the unique challenges this population faces, and the limited research on the specified group, it is crucial for social work professionals to continue to evaluate additional ways to support them, conduct research, and advocate for their needs.

APPENDICES

APPENDIX A

RECRUITMENT FLYER

Appendix A

Do you have a sibling with Autism Spectrum Disorder?

You have a unique story that often does not get told.

I am currently a graduate student at California State University, Long Beach studying for my Masters degree in Social Work. I am conducting research for my thesis entitled,

"The Adult Sibling's Experience of Aggressive Behaviors in Children with Autism Spectrum Disorder: A Qualitative Study"

If you are at least 18 years old and your sibling had aggressive behaviors growing up I want to hear your story. It is hoped that the results from the study will give a more complete understanding of siblings' unique experiences in order to continue to develop more effective ways to support them. Participation in the study will require an interview that will last approximately 30 minutes.

If you would like to participate or want more information, please contact me at xxx-xxx-xxxx or xxxxxxxxxx@xxxxx.com.

If you have any questions about the study you may contact my thesis advisor, Dr. Ruth Chambers, at ruth.chambers@csulb.edu.

APPENDIX B

INFORMED CONSENT

Appendix B
CONSENT FORM

The Adult Sibling's Experience of Aggressive Behaviors in Children with Autism Spectrum Disorder: A Qualitative Study

CONSENT TO PARTICIPATE IN RESEARCH

I am Cristiana Salucci, a Master's of Social Work student at California State University, Long Beach. I am inviting you to participate in a study I am conducting for my thesis. You were selected as a possible participant in this study because you are at least 18 years old and have an aggressive sibling diagnosed with Autism Spectrum Disorder.

PURPOSE OF THE STUDY

The purpose of this study is to better understand the unique experiences adult individuals had growing up with a sibling with Autism Spectrum Disorder.

PROCEDURES

Your participation is completely voluntary. If you choose to participate in this study you will be asked to participate in a face to face interview. You will also have the option to conduct the interview over the telephone. All of the information you provide is confidential. I will interview you in a private location of your choice or via telephone. The interview should take approximately 30 minutes of your time. The interview will be audiotaped, with your permission. If you do not wish to be audiotaped, I will only take hand-written notes. You will not have the opportunity to review your audiotape or transcript. The audiotapes will be destroyed after completion of the project and all related materials will be destroyed after three years.

POTENTIAL RISKS AND DISCOMFORTS

Minimal risks are anticipated. However, some participants may find that the interview questions bring up sensitive feelings or difficult emotions due to the personal nature of the questions. If you are uncomfortable with any of the questions, you have the right to abstain from answering and may withdraw from the study at any time without any consequences to you. Your responses will remain confidential. Your name will not be revealed in any portion of the written report.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

You are not expected to benefit directly from this research. However, it is hoped that the results will assist other social workers and professionals to better understand these experiences and provide the appropriate services.

PAYMENT FOR PARTICIPATION

There is no payment for participation.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential with the exception as when required by law. I am required to report any information that is illegal and/or could result in harm to self or others. No individual names will be used in any report of the results. The researcher and thesis advisor will be the only individuals who will know who has participated in the study and the only ones with access to the research materials. All audiotapes will be destroyed after the data has been transcribed.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. Participation or non-participation will not affect your benefits or any other personal consideration or right you usually expect. You may also refuse to answer any questions you do not want to answer and still remain in the study.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the study, please feel free to contact me at xxx-xxx-xxxx or my thesis advisor, Dr. Ruth Chambers, at xxx-xxx-xxxx or ruth.chambers@csulb.edu.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, you may contact the Office of University Research, California State University, Long Beach, 1250 Bellflower Blvd., Long Beach, CA 90840. Or you may telephone at 562-985-5314 or email to
ORSP-Compliance@csulb.edu.

VERBAL CONSENT OF RESEARCH PARTICIPANT

I understand the procedures and conditions of my participation described above. My questions have been answered to my satisfaction, and I gave verbal consent to participate in this study.

Approved from December 3, 2014 to December 2, 2015 by the CSULB IRB

APPENDIX C

INTERVIEW GUIDE

Appendix C

Interview Guide

I first would like to start by thanking you for your time and participation in this research. The interview will last approximately 30 minutes and ask questions about your sibling experience. Do you have any questions before we begin?

1. Tell me about your experience being a sibling of someone with Autism Spectrum Disorder.
    a. Probe- Where are you in the birth order in relation to your sibling?
    b. Probe- What is one of your earliest memories of understanding or learning he/she had autism? How old were you?

2. Tell me a little about your sibling with autism.
    a. Probe- How would you classify his/her functioning level? Verbal or non-verbal?
    b. Probe- What sort of behaviors did he/she exhibit?
        i. Probe if no aggression mentioned: Did they ever have aggressive behaviors?
    c. Probe- How old were you when he/she were diagnosed?

3. What was your responsibility in caring for your sibling?
    a. Probe- When you were younger?
    b. Probe- Do you have any responsibilities caring for them now?

4. How was your childhood impacted by your sibling?
    a. Probe- The impact on your family life?
    b. Probe- The impact on your school life?
    c. Probe- The impact on your personal life?

5. What was the most challenging thing about your sibling growing up?
6. What is the most rewarding thing about having a sibling with autism?
7. What advice would you give to a brother or sister of someone with autism?
8. What recommendations do you have for social workers and other professionals that assist this group?

Now I would like to ask you some demographic questions.

1. What race/ethnicity do you identify yourself as?
2. Are you currently working or going to school?
3. Were you parents together or separated growing up?
4. Who lived in your home with you growing up?
5. What is your age?

Is there anything else you would like to tell me that we haven't talked about yet?
Thank you so much for your time. Your participation is extremely valuable to me and I appreciate it.

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