

2-8-2024

Lived Experiences of Young Adults Raised With a Sibling With Autism

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Walden University

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Walden University

College of Psychology and Community Services

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Lamika Thomas

has been found to be complete and satisfactory in all respects,
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the review committee have been made.

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Walden University
2024

Abstract

Lived Experiences of Young Adults Raised With a Sibling With Autism

by

Lamika Thomas

MSW, The Ohio State University, 2005

BA, Earlham College, 2003

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services

Walden University

February 2024

Abstract

When a child has autism spectrum disorder (ASD), the family structure is affected. Although researchers have documented increased stress and depression among parents of children with ASD, they have not adequately explored siblings' perspectives on the emotional, physical, and/or psychological implications of having a brother or sister with ASD. The purpose of this qualitative phenomenological study was to explore siblings' lived experiences of growing up in a household with a sibling with ASD. The conceptual framework for this study was grounded in the siblings embedded systems framework (SESF), which helps contextualize siblings' experiences, including interacting factors, and how these experiences affect siblings' relationships with siblings and other family members. Semi structured interviews were conducted, via the Zoom videoconferencing platform, with six young adults who had grown up in a household with a sibling who was diagnosed with ASD. Data analysis yielded five key themes: communication, stress, support systems, feelings, and responsibility. Participants expressed being scared and/or fearful, and they indicated a desire for early intervention from professionals to increase communication and interactions with their sibling diagnosed with ASD. The study may foster positive social change by increasing professionals' understanding of how-to best support siblings of individuals with ASD. SESF may be useful in helping all professionals (i.e., therapists, caregivers, social workers, etc.) to understand how childhood experiences can affect siblings.

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Dedication

I would like to dedicate this dissertation to my grandfather James B. Carter Sr., who passed away on September 15, 2005, my uncle Richard D. Carter, who passed away on March 27, 2011, and my uncle, James B. Carter Jr., who passed away on December 13, 2019. My grandfather and uncle were two of my biggest supporters, motivators, encouragers, and father-like figures in my life. Although they are not physically present, I know that they are still supporting me spiritually. Thank you, Granddad and Uncle James! I miss you and love you so much!

Acknowledgments

First, I would like to thank God for blessing me with this opportunity. This journey has not been easy, but I am here, and I made it. Second, Dr. Scotten, words cannot express how much you mean to me in this journey. I am amazed at your dedication, motivation, and consistency as a professor, mentor, and committee chair. I was broken, confused, and frustrated when I switched over to you (in the middle of writing my prospectus), and you just said, “Breathe, we are going to get through this.” Thank you so much, and I appreciate you.

Third, I want to thank my husband, Marc A. Thomas II, for believing in me and not allowing me to give up. There were days when I wanted to throw in the towel and settle with having a master’s degree. Honey, thank you for the “tough love.” You knew how to create a balance of just being a shoulder to cry on and providing that firm push when I needed it most. Fourth, I would like to thank Symiah, Malia, Joshua, Zahara, Micah (my children) and Layla (my sister) for supporting me. Last, I would like to thank my mother, Sarah Carter. When I was a little girl, I always told her that I wanted to be a doctor to help people. Throughout my doctoral career, there has been a lot of illness, pregnancies, and many life-changing events, but my mother has always reminded me of that childhood goal. Thank you, Mom!

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Chapter 1: Introduction to the Study

When a child has autism spectrum disorder (ASD), the family structure is affected. There is an increase in parenting stress and depression (Martinez-Pedraza & Carter, 2009). Relationships with siblings, and the potential for sibling stress, are equally important when discussing how the family dynamic is different with a child with autism. The emotional, physical, and/or psychologically well-being of siblings can be negatively affected (Martinez-Pedraza & Carter, 2009).

Investigation of sibling relationships and experiences is important to develop a clear understanding of what it is like to be raised in a household with a sibling with ASD. In this study, I focused on how individuals whose siblings have ASD perceived their household, upbringing, behaviors, interactions, and attitudes towards their parents/caregivers and sibling(s). This provided an opportunity to understand how having a sibling with ASD affected their childhood and adulthood. My goal was to gain more insight into sibling experiences by as conveyed by siblings themselves. Chapter 1 includes an overview of the study I conducted. The potential implications for positive social change include generating information that might increase mental health professionals' understanding of how-to best support siblings of individuals with ASD. This chapter addresses the following: background of the study, problem statement, purpose of the study, research question, conceptual framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance.

Background

ASD impacts approximately 1 out of every 150 children in the United States (Martinez-Pedraza & Carter, 2009). According to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013), a child must meet the following symptoms to meet the full criteria for an ASD diagnosis:

- “There is a deficit in social communication and interactions in multiple areas, such as interests, emotions, and affect. There is a failure to have normal reciprocal conversations with others” (p. 1).
- “Individuals also show a deficit in nonverbal communication, which means eye contact, facial expressions, body language or deficits in understanding and use of gestures” (p. 1).
- “There are deficits in developing, maintaining, and understanding relationships, such as individuals adjusting to imaginative play, initiating friendships or playing games with friends. There is a lack of interest in peer relationships” (p. 2).
- “There are restricted, repetitive patterns of behavior, interests, or activities, in at least two area” (p. 3).

The areas are

- “Repetitive motor movements, use of objects, or speech (i.e., lining up of toys, stemming behaviors, or repeated phrases)” (p. 3).
- “Insistence on consistency; a need for structure or sameness, such as eating the same meals, or having the same routine” (p. 3).

- “Highly restricted, fixated interests on unusual objects or items (i.e., fixated on aluminum foil)” (p. 4).
- “Hyper-or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, sensitivity to sounds/smells, etc.)” (p.4).

To meet the criteria for an ASD diagnosis, symptoms must be present in the early developmental period and cause clinically significant impairment in social, occupational, or other important areas of current functioning. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay (Hodges et al., 2020). These symptoms significantly impact language, communication, social skills, comprehension, behaviors, and the building of relationships. However, there are early intervention and screening processes that help parents or caregivers identify ASD-like behaviors to confirm a true diagnosis, such as assessments with speech and language pathologists (Martinez-Pedraza & Carter, 2009).

Siblings of children with ASD and Down syndrome have a greater emotional fragility and greater need for mental health support. Research shows that siblings of children with disabilities are more at risk for the development of mental health disorders (Caliendo et al., 2020). It is therefore important for mental health workers to address the mental and emotional health well-being of healthy siblings (Caliendo et al., 2020).

Growing up with a sibling with ASD can affect the quality of the sibling relationship (Pollard et al. 2013). Researchers have generated greater understanding of the sibling dynamic in families with children with developmental disabilities (Pollard et

al., 2013). They have found that decreasing the number of negative interchanges within the sibling relationship might decrease the level of anxiety the typically-developing sibling reports. This indicates that therapeutic interventions that address ASD sibling relationships might increase social support and decrease the number of negative interchanges within the sibling relationship (Pollard et al., 2013).

There has not been much research done on sibling experiences growing up with a disability (Longobardi et al., 2019). Researchers have examined sibling relationships when one sibling has an intellectual or developmental disability, but there is less research focused on sibling relationships during adulthood and of the carryover of siblings' feelings from childhood experiences (Orsmond & Fulford, 2018). The majority of the existing research on sibling impacts has focused on information obtained from parents (Caliendo et al., 2020; Martinez-Pedraza & Carter, 2009; Pollard et al., 2013). Therefore, it is important to add to the body of literature by including information from siblings.

Problem Statement

Children with ASD lack social skills, communication skills, and interactive skills (American Psychiatric Association, 2013; Martinez-Pedraza & Carter, 2009). For this reason, there are psychological and mental health implications of growing up with a sibling with ASD (Chan, 2016; Hastings & Petalas, 2012; Solmeyer & Mchale, 2012; Soysal, 2016). These issues can continue and become more pronounced as the child gets older, especially when they reach adolescence (Soysal, 2016). Prior research exists regarding sibling experiences of living in the same household with a brother or sister with ASD. This research indicates that the quality of sibling relationships may be affected by

the sibling having adjustment issues with the ASD individual (Chan, 2016). Siblings of those with ASD experience more externalizing and internalizing symptoms than siblings of children with other disabilities (Fisman et al., 2000; Hastings & Petalas, 2012). Siblings may also have significant issues with peer interactions and the development of appropriate social skills (Kao et al., 2011; Zucker et al., 2021). The literature supports that individuals who are raised with a sibling with ASD have an increased risk for the development of mental health, emotional, or behavioral concerns (Caliendo et al., 2020; Feinburg et al., 2012).

There are some studies of the relationships between individuals and their sibling with ASD, but the majority of the research has been based on parents' perspectives of those sibling relationships (Caliendo et al., 2020; Martinez-Pedraza & Carter, 2009; Pollard et al., 2013). Only including the parental perspective can lead to false reporting or incomplete conclusions about the experiences of siblings themselves (Hastings, 2014). The reasons are that the parents in such studies report their thoughts about what their child(ren) may be feeling. The data should be directly obtained from the siblings (Latta et al., 2013). There are few studies that discuss experiences of siblings of those who have ASD in the family (Hastings, 2014; Kovshoff et al., 2017; Latta et al., 2013).

Purpose of the Study

The purpose of this phenomenological qualitative study was to explore siblings' lived experiences growing up in a household with a sibling with ASD from a retrospective perspective. My goal was to speak directly to individuals who grew up in a family where one of their siblings was diagnosed with ASD and to elicit their lived

experiences. I wanted to provide a better understanding of this issue from the siblings' perspective. The potential contribution includes generating information that might increase mental health professionals' understanding of how-to best support siblings of individuals with ASD. This understanding may help professionals to implement early therapeutic interventions between siblings during sibling crisis situations.

Research Question

What are siblings' lived experiences growing up in a household with a sibling with ASD?

Conceptual Framework

The conceptual framework for this study was grounded in the siblings embedded systems framework (SESF). SESF is a framework that helps contextualize siblings' experiences, including interacting factors, and how these experiences affect their relationships with siblings and other family members (Kovshoff et al., 2017). Professionals can use the SESF to understand how siblings' experiences of growing up influence their adjustment from childhood to adulthood (Kovshoff et al., 2018).

SESF is applicable to all families, including ASD ones. Sibling relationships are one of the most important relationships that a person will have in their lifetime (Caliendo et al., 2020; Chan, 2016; Hastings & Petalas, 2012; Solmeyer & Mchale, 2012; Soysal, 2016). SESF can be used to provide an understanding of sibling relationships that can be used to help improve sibling dynamics, relationships, and the overall well-being of all who live in the household (Kovshoff et al., 2017). Not only can the use of SESF help improve sibling relationships, but it can also improve the siblings' understanding and

acceptance of ASD (Zucker et al., 2021). SESF is focused on topics, such as educational awareness, enhanced self-esteem, positive communication and social skills, life achievement, academic success, mental health impairment, and overall health. Firsthand accounts of how individuals are affected in these areas can assist professionals in intervening in a positive way (Kovshoff et al., 2017).

Nature of the Study

I selected a qualitative, phenomenological methodology to answer my research question. By using the phenomenological approach, I was able to engage participants in discussion about their personal experiences and to encourage them to share important details about their childhood. The phenomenological approach is a form of qualitative research that focuses on individuals' lived experiences within the world (Aspers & Corte, 2019). Phenomenological research is very intimate and deep, and reflects firsthand experiences (Creely, 2018). Phenomenology is a qualitative research methodology that focuses on phenomena as they are manifested through real lived experiences (Valentine et al., 2018). Another reason for using this approach was that it allowed for themes, phrases, and concepts to evolve from the collected data.

I collected data from individuals who met the criteria of being young adults, age 18–25, who grew up in a household with a sibling with ASD and who did not currently live in the family home with the sibling. I did not select individuals who currently resided in their parents' home out of concern that their answers would be biased or skewed. Semi-structured interviews were conducted with participants.

Definitions

The following terms are defined to help the reader understand the meaning of each term in this study:

Psychosocial adjustment: The behavioral process of balancing conflicting needs, or needs challenged by obstacles in the environment (Petalas et al., 2012).

Sibling influences: Sibling contact and companionship during childhood and adolescence—increasingly outside the direct supervision of adults or parents—that provides ample opportunity for siblings to shape one another’s behavior and socioemotional development and adjustment (O’Brien et al., 2011).

Assumptions

An ontological assumption undergirded this qualitative study. The premise of ontology is that the nature of reality is subjective (Dinsmore, 2017). Reality is subjective, and the nature of communication is derived from the subject’s perspective. I assumed that all participants answered the interview questions honestly and completely during the interview process. The study relied on participants’ provision of honest answers about their experiences. I assumed that all participants gave truthful reports regarding their brother’s or sister’s ASD diagnosis and experiences they had with that sibling. All participants volunteered for the study and were assumed to have a sincere interest in participating and not to have any other motives or incentives.

Scope and Delimitations

I collected data from individuals aged 18–25 who grew up in a household with a sibling with ASD and who did not currently live in the family home with the sibling

diagnosed with ASD. Young adults were the only age group to be used because this is the developmental stage when most individuals, in the United States, leave their parents household (Wang et al., 2013). I included only those who were at least 18 years of age as these individuals were able to consent to participate without parental consent. I did not select participants who currently resided in their parents' home out of concern that their answers would be biased or skewed. Individuals residing at home may be reluctant to disclose certain information because they do not want to upset their parents (Wang et al., 2013).

The delimitation of this study was that participants were limited to those who had access to social media. A larger and more geographically diverse sample may provide more insight into issues with siblings with ASD. I might have discovered more information had I not restricted the study to a specific geographical location or specific platforms. The selection of participants in a different age range and/or not still living in their parents' home may also have yielded different information.

Limitations

There are a few limitations for this research. First, I used an epoche approach due to my professional background and experience (see Zahvi, 2019). As a licensed social worker, I have a professional background with mental health and therapeutic services. My major client base includes persons diagnosed with autism and their families. These individuals have expressed the need for professionals to start intervening with siblings sooner versus later. I wanted to find ways to improve sibling dynamics, but I wanted to make sure that my background working with the population of interest did not interfere

with the collection of data. For instance, I did not want participants to sense my passion and skew their answers for the benefit of my research. Therefore, due to my professional background, I conducted this study with an epoché approach. Epoché means conducting research without any pre-stereotypes or biases (Zahvi, 2019). My goals were to discuss firsthand experiences with individuals who were raised in a household with a sibling with ASD, to identify themes that emerged about individual experiences with their sibling with ASD, and to provide information for professionals about interventions they can potentially use to help individuals who have a sibling with ASD.

I conducted the interviews via Zoom. Therefore, I was able to interview only people who had access to an electronic device (i.e., computer, iPhone, etc.) and the internet. This is a limitation because some issues associated with electronic devices, such as call connection and audio/video reliability and quality, had the potential to adversely affect data collection (Archibald et al., 2019). Third, the participants were limited to volunteers. Therefore, this study's finding cannot be generalized beyond the participants (Howlett, 2021).

Significance

Siblings of individuals with ASD may have depressive symptoms related to the behavioral problems of their ASD sibling (Kolber-Jamieson, 2020). Additional challenges for siblings of individuals with ASD include a lack of social and interactive skills (Pollard et al., 2013), sibling rivalry (Latta et al., 2013), and academic difficulties (Peterson et al., 2013). The potential contribution of this study may be the generation of information to help professionals increase their understanding of how-to best support

siblings of individuals with ASD. With such knowledge, professionals may be able to assist with early therapeutic interventions between siblings if sibling crisis situations arise.

Summary

According to the literature, sibling interactions are one of the most important interactions that one will have in a lifetime (Caliendo et al., 2020; Chan, 2016; Hastings & Petalas, 2012; Solmeyer & Mchale, 2012; Soysal, 2016). My goal in conducting this study was to provide professionals with more insight on siblings' firsthand experiences of growing up with individuals with ASD. There was little research on this topic from a sibling's perspective; the primary research consisted of the parental view of the relationships between their children (Hastings, 2014; Kovshoff et al., 2017; Latta et al., 2013). I used a qualitative phenomenological approach to capture siblings' lived experiences growing up in a household with a sibling with ASD. Results of this study may benefit multiple professionals, including therapists and counselors, by informing them about therapeutic interventions that they can potentially use to support relationships between siblings when one individual has ASD. In Chapter 2, I review key literature related to the study. In addition to discussing the literature search strategy, I provide more information on the conceptual framework for the study.

Chapter 2: Literature Review

Introduction

The experiences of siblings who grew up with a brother or sister with ASD have received some scholarly attention. The quality of sibling relationships may be impacted by the sibling having adjustment issues with the ASD individual (Chan, 2016). Siblings of those with ASD experience more externalizing and internalizing symptoms than siblings of children with other disabilities (Fisman et al., 2000; Hastings & Petalas, 2012). Siblings may also have significant issues with peer interactions and the development of appropriate social skills (Kao et al., 2011; Zucker et al., 2021). Individuals who are raised with a sibling with ASD have an increased risk for the development of mental health, emotional, or behavioral concerns (Caliendo et al., 2020; Solmeyer & Mchale, 2012).

Researchers have studied the relationships between individuals and their sibling with ASD, but the majority of the research has been based on parents' perspectives of sibling relationships (Caliendo et al., 2020; Martinez-Pedraza & Carter, 2009; Pollard et al., 2013). Only including the parental perspective can lead to false reporting or incomplete conclusions about the experiences of siblings themselves (Hastings, 2014). The reason is that the parents in these studies report their thoughts about what their child(ren) may be feeling. There are few studies that discuss experiences of siblings of those who have ASD in the family (Hastings, 2014; Kovshoff et al., 2017; Latta et al., 2013).

The purpose of this phenomenological qualitative study was to explore siblings' lived experiences growing up in a household with a sibling with ASD. My goal was to speak directly to individuals who grew up in a family where one of their siblings was diagnosed with ASD. I wanted to learn more about these individuals' lived experiences, in an effort to better understand the study topic from their perspective. The potential contribution may be an increase in professionals' understanding of how-to best support siblings of individuals with ASD. With this understanding, professionals may be better able to devise early therapeutic interventions if sibling crisis situations arise. In this chapter, I review the literature related to key variables and/or concepts. The literature search strategy and conceptual framework for the study are also addressed.

Literature Search Strategy

For my literature search strategy, I used relevant resources from the Walden University Library, in addition to the application Google Docs and the Yahoo! search engine. I obtained articles from three Walden Library databases: SAGE, ProQuest Dissertations and Theses, and Education Resources Information Center (ERIC). I also searched Walden psychology, social work, and human services subject-specific resources. Keywords that I used in this search included *autism*, *autism and siblings*, *sibling influence and autism*, *sibling impact and autism*, *sibling perspective and autism*, *sibling experience and autism*, *autism with childhood experiences*, *siblings embedded systems framework*, *adult siblings of ASD individuals*, and *adult experiences with ASD siblings*. When reviewing some of the research, I found other resources that were identified in those articles. Most research focused on the parental viewpoint and how the parent felt

the household environment affected the ASD individual and their siblings. The rest of the research articles I found focused on relationships and perspectives discussed from parents' point of view. The goal of my research was to hear directly from the siblings.

Conceptual Framework

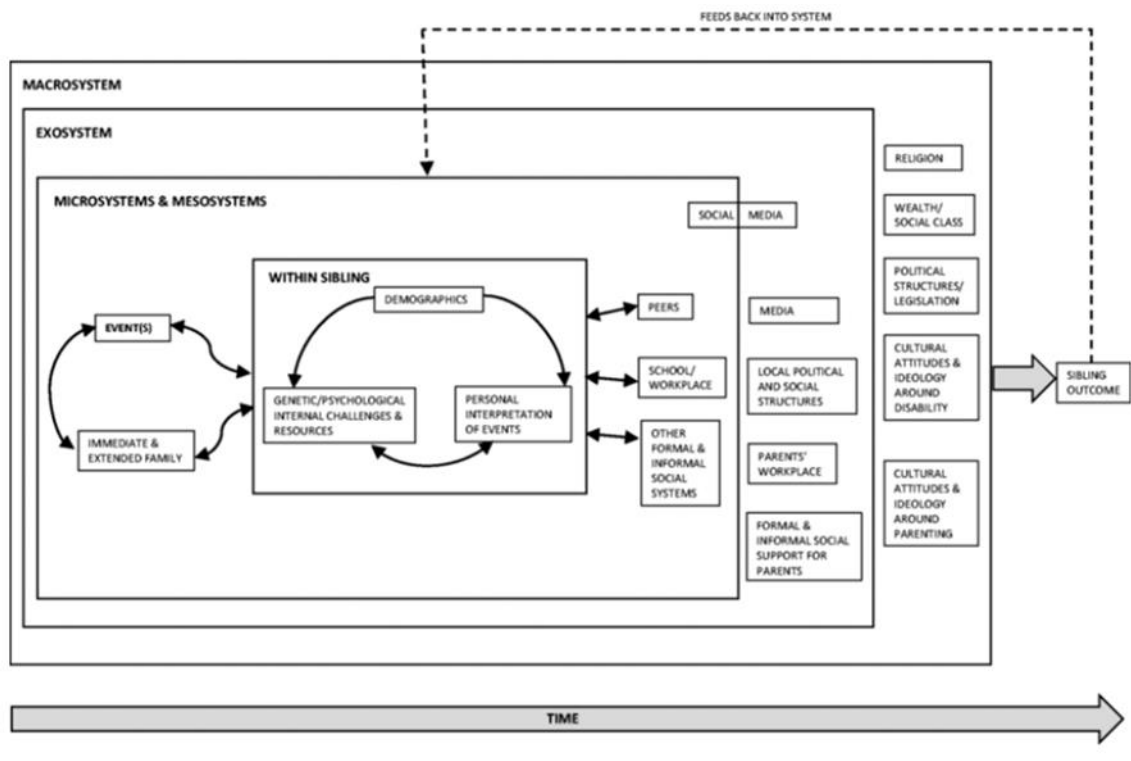
The conceptual framework utilized for this study is the SESF. SESF is a framework that incorporates elements of the family systems model, the double ABCX model, the diathesis-stress model, and the bioecological systems model. Kovshoff et al. (2017) developed the SESF approach to explain factors that affect sibling adjustment and to develop clinically, educationally, and empirically based work to enhance and support sibling adjustment, relationships, and well-being in families of children with autism. This framework is not specific to disability research, but is specific to the “particular context of understanding siblings of children with autism” (Kovshoff et al., p .39).

Primary Components

In using a combination of the four models, SESF was designed to understand siblings' experiences and how they impact their relationships with different family members (Kovshoff et al., 2017; Zucker et al., 2021). Kovshoff et al. (2017) argued that a combination of these four models could be a key component in helping researchers understand factors that impact siblings and how to best support them. The components that were identified in the SESF include *within sibling*, *microsystems and mesosystems*, *exosystem*, and *macrosystem* related interactions and experiences (Kovshoff et al., 2017; see Figure 1).

Figure 1

Components of the Siblings Embedded Systems Framework



Note. From “Siblings of Children With Autism: The Siblings Embedded Systems Framework,” by H. Kovshoff, K. Cebula, H.-W. J. Tsai, & R. P. Hastings, 2017, *Current Developmental Disorders Reports*, 4(2), p. 39 (<https://doi.org/10.1007/s40474-017-0110-5>). Copyright 2017 by H. Kovshoff, K. Cebula, H.-W. J. Tsai, & R. P. Hastings. CC BY 4.0 DEED.

Within Sibling

The SESF does not specifically focus on disabilities, but the understanding within sibling experiences. In Figure 1, “event” can be defined as the impact on the sibling, but

the impact will be different based on interactions with siblings, demographical situations, internal challenges and resources, and the sibling's interpretation of the events.

Demographics. Demographic characteristics have all played a role with sibling outcomes, especially when siblings have autism (Kovshoff et al., 2017). These characteristics include gender, race, family status, race, income, and age. In utilizing SESF, the overall number of demographic risk factors can be a key component in predicting sibling outcomes.

Genetic/Psychological Internal Challenges and Resources. Genetic and psychological internal challenges and resources is another area that gives a more detailed account in understanding sibling experiences. Internal challenges are defined as any struggles, conflict, or tension that can impact the sibling dynamic (Kovshoff et al., 2017). The challenges are anything that are identified within the siblings. This can include positive self-esteem, positive interactions, being resilient, or utilizing adaptive social skills.

Personal Interpretation of Events. The final impact within the sibling factor is the sibling's personal interpretation of the event. The sibling will reflect on any interactions they may have had with their autistic sibling, and reflect solely on the positive components.

Interactions between the within sibling factors (demographic variables, genetic/psychological internal challenges and resources, and personal interpretation of events) may also differ based on sibling ages (Kovshoff et al., 2017).

Microsystems and Mesosystems

SESF includes multiple levels within siblings, which includes micro-systems (directly experienced by the sibling), the meso-systems (the sibling does not directly participate), macrosystems (influence of social and culture impact), and the exosystems (the interplay between the macro and microsystems) (Kovshoff et al., 2017). Within the micro and meso system levels, event is one of the key components.

Events. The event could be the individual identified with autism, however, the important factor with SESF is making sure that the child is not viewed in a negative way. Event can be used interchangeably based on the needs of the family. Therefore, event can be referred to as the neurotypical identified sibling, or a specific behavior (i.e., arguing between siblings) that may be occurring. Event is whatever is important to help enhance interactions between siblings.

Immediate and Extended Family. Other factors, such as immediate and extended family members, are also important factors that can impact siblings within the micro and meso level. Within the immediate/extended family, siblings can be impacted by parent/adult figures relationship quality, stress in the household/environment, parental/adult figure mental health, or tension between parental figures and other adult figures, or any other (Kovshoff et al., 2017). Research shows that family social support moderated the impact of symptom severity and better sibling adjustment in families using early autism interventions (Mchale et al., 2012). The impact of immediate and extended family members is also determined by how close the interactions are within the siblings.

Peers. There is limited research on the impact that peer interactions have within siblings (Kovshoff et al., 2017). However, it is important to note that positive social and peer interactions could have a positive impact on one's sibling experiences.

School/Workplace. There is also limited research on the influence that school factors have within siblings. School factors include: both siblings attending the same school, inclusive school attitudes, or the sense of school connectedness (Kovshoff et al., 2017). More research needs to be done in this area.

Other Formal and Informal Social Systems. Other formal and informal social systems for siblings may include churches, clubs, extracurricular activities, community membership, and any other social systems that are identified as supportive. This is another area that has limited research.

Exosystem

Besides the micro and mesosystems level, the SESF includes the exosystem. The exosystem is defined as one or more settings that do not directly involve the developing person as an active participant, but the individual is still impacted (Newman & Newman, 2020). For instance, in perspective of my study, a sibling may feel unwanted by their parent because of all the attention that their autistic sibling may receive. In SESF, there are other settings that can cause an indirect impact within siblings.

Social Media/Media. Social media and other media influences are a part of the exosystem level that impacts siblings. Social media/media continuously changes and can impact siblings based on how much exposure and influence that it has over their life. For instance, siblings may not want to hang around their sibling with autism because they

may feel they are not “cool” in the eye of social media. However, little is known as to how much of a role social/media play within siblings (Kovshoff et al., 2017).

Local Political and Social Structures. Local political and social structures refer to the interactions within the political system, the regulations, laws, and the values that a person has within that system. Within the exosystem level, there is limited information on how much local political and social structures impact siblings, but it could be influential (Kovshoff et al., 2017).

Parents’ Workplace. An individual’s work environment can impact work performance, interaction with others, and overall attitude. When parents are happy and enjoy their work environment, they have healthier and happier relationships (Kovshoff et al., 2017). The impact that parents’ workplace has within siblings, is still an area that needs further investigating.

Formal and Informal Social Supports for Parents. Formal and informal social supports for parents include churches, support groups, community membership, and any other social systems that are identified as supportive. This is another area that has limited research.

Macrosystem

Finally, the macrosystem refers to the culture or cultural influences that frames the structures and relationships among the systems (Newman & Newman, 2020). Based on the SESF approach, these cultural influences must directly impact the siblings (Kovshoff et al., 2017).

Wealth/Social Class. For families, wealth and social class can also play a role and impact siblings. Growing up in a lower class or disadvantaged community could mean less access to resources for the family (Kovshoff et al., 2017). However, this is an area that is limited in research too.

Political Structure/Legislation. Political structure and legislation refer to the interactions within the political system, the regulations, laws, and the values that a person has within that system. However, within the macrosystem level, the focus is the impact that politics plays in the sibling relationship.

Religion, Cultural Attitudes, and Ideology Related to Disability. Religion and Culture are two major influential examples in the macrosystem level that impacts sibling outcomes. Culture is referred as the ideas, customs, and behaviors of particular group of people, the values that they believe in, and the traditions that are followed (Kovshoff et al., 2017). Religion is referred to as a particular system of faith or worship (Newman & Newman, 2020). Within my study, siblings' attitudes and belief around people with disabilities will have a significant impact on sibling interactions. Culture influence and religion can determine how people act and interact with others.

Cultural Attitudes and Ideology Related to Parenting. Within the family dynamic, culture can play a role in parenting styles and the parent/child interactions (Kovshoff et al., 2017). In some situations, culture can also impact parents' feelings about seeking help or having professional involvement. In some cultures, seeking professional support can be viewed in a negative way.

Other Components

There are two components left that encompasses the SESF, which is sibling outcome and the notion of time. Sibling outcome refers to sibling adjustment, psychosocial adjustment, sibling relationship quality, academic achievement, or life satisfaction/quality of life (Kovshoff et al., 2017). The hope for SESF is that it feeds back into the system. Siblings with more positive supports are likely to interact in a better way with the sibling with autism versus if there were more stress factors (Kovshoff et al., 2017; Newman & Newman, 2020).

Time is also equally important within this framework since there are certain components (i.e., autism diagnosis) that remain consistent throughout siblings' lifetime (Kovshoff et al., 2017). Also, earlier experiences are the beginning stepping stones to shaping one's life. As adults, siblings may treat each other in a positive/negative way, depending on all of the factors that have been listed in the macro, micro/meso, and exosystem. In my study, the SESF is a chance to enlighten professionals on the impact that having an autistic sibling has had on their life.

Interaction of All Components

There is research that discuss specific components within SESF, such as psychosocial adjustment (Hastings et al., 2012) and peer interactions (Kao et al., 2011; Zucker et al., 2021), however, there is no research that explain how the interactions of all levels and components impact siblings (Kovshoff et al., 2017). The interaction of all components is a phenomenon that should be explored further.

Literature Review Related to Key Variables and/or Concepts

Autism Spectrum Disorder

ASD is a neurological and developmental disorder that begins in early childhood and remains throughout a person's lifetime (Parmeggiani et al., 2019). Autism impacts approximately 1 out of every 59 children in the United States (Parmeggiani et al., 2019). According to the *DSM-5* (American Psychiatric Association, 2013), the criteria for ASD reflects the following symptoms:

Qualitative impairment in social interaction as manifested by two of the following: impairment in the use of nonverbal behaviors (i.e., eye gaze, facial expression body postures), failure to develop peer relationships, lack of sharing of enjoyment, or lack of social or emotional reciprocity. Socially, ASD individuals may not have the skills to interact with people in an appropriate way or social settings may be too overwhelming.

Qualitative impairment in communication in at least one of the following areas: delay or total lack of spoken language, marked impairment in the ability to initiate or sustain a conversation with others, stereotyped or repetitive use of language, or lack of varied spontaneous play. With language, ASD children mainly repeat words in an 'odd intonation' or repeat the same phrase exactly as they heard. ASD children also may show deficits in their nonverbal communication. For instance, they may look at people less, smile less, and could have lack of social/emotional communication.

Restricted repetitive and stereotyped patterns of behaviors, interests, and activities as manifested by preoccupation with one or more restricted patterns of interests, inflexible adherence to nonfunctional routines or rituals, repetitive motor mannerisms, or preoccupation with parts of objects. ASD individuals may experience behavioral issues, such as physical aggression, tantrums, screaming, crying fits, and many others, just because they are not able to communicate their needs.

Deficits in developing, maintaining, and understanding relationships (including adjusting behavior in various social contexts, difficulties in sharing imaginative play or in making friends, or lack of interest in peers)

Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). (p. 163)

At age 3 or older, a diagnosis of ASD can be considered very reliable when given by a medical professional. However, autism can be difficult to diagnose because there are no medical tests, or blood tests that can assist with this diagnosis (American Psychiatric Association, 2013). Autism can also be misdiagnosed. The most common misdiagnoses are intellectual disability, psychoses, personality disorder, depression, ADHD, and various other disorders (Fussar-Poli et al., 2020).

Doctors have to follow medical protocols before confirming an ASD diagnosis (Parmeggiani et al., 2019). Protocols include talking to parents, day care providers,

therapists, and/or other professionals, to determine the child's developmental history.

Doctors do their research by developmental monitoring, developmental screening, and comprehensive developmental evaluations. All three of these areas have to be taken into consideration before confirming a diagnosis (Parmeggiani et al., 2019). The specific aspects of each area are as follows:

1. **Developmental monitoring:** Milestone observations of child growth and changes over time and whether the child meets the typical developmental milestones in playing, learning, speaking, behaving, and moving. These milestones are observations from primary care doctors and physicians. This developmental monitoring is crucial during the first 3 years.
2. **Developmental screening:** A review of how the child is developing through developmental and behavioral screenings. These screenings ask questions about development, including language, movement, thinking, behavior, and emotions.
3. **Comprehensive developmental evaluation:** The formal evaluation is usually done by a child psychologist, speech-language pathologist, or other specialist. It may involve observations, structured tests, or asking the parents to fill out questionnaires (Parmeggiani et al. 2019). The results of this formal evaluation determine whether a child will be formally diagnosed with Autism and treatment recommendations (Fusar-Poli et al., 2020).

The clinical presentation of ASD is believed to be multifaceted, originating from a complex interplay between genetic and environmental factors (Parmeggiani et al.,

2019). Though the exact cause of ASD is still unknown, a diagnosis has a significant impact on the child, family, siblings, and sibling relationships (Latta et al., 2013; Peterson et al., 2013; Zucker et al., 2020).

Implications of an Autism Spectrum Disorder Diagnosis for Families

Relationships may become more complex when involving a child who has a disability. There is an increase of parenting stress, sibling stress, family stress (Martinez-Pedraza & Carter, 2009) and mental health disorders (Caliendo et al., 2020) when there is a child with a disability within the family. In most families, having an ASD diagnosis means professional involvement, which may include behavior specialist, communication specialist, respite care, therapy, and many other support systems. The increase in support systems can be very stressful for parents and means that there is a lot of time that is dedicated to the child with ASD. Besides an increase amount of time and dedication, a diagnosis of ASD impacts many other factors in the household such as, housekeeping, finances, emotional and mental health of parents, marital relationships, physical health of family members, sibling relationships, and leisure activities (Begum & Mamin, 2019; Zucker et al., 2021). As a result, there is an increase in parental stress when raising a child with ASD and handling all other factors of one's life (Begum & Mamin, 2019; Torchetti-DiPrima, 2018).

Individual With Autism Spectrum Disorder

ASD affects a child's nervous system, brain, motor movement, and growth and development (Latta et al., 2013, Peterson et al., 2013; Zucker et al., 2021). Since ASD impacts the nervous system, children with autism can often find it difficult to manage

normal daily living skills and tasks, such as brushing teeth, communicating with others, or having appropriate conversations. Children with ASD may have trouble in school environments since there are limitations on communication skills, understanding social situations, and having appropriate social skills (Begum & Mamin, 2019). They often have limited abilities on how to effectively communicate their needs and desires, and often times negative behaviors are the end result (Zucker et al., 2021).

Parents

Parents are faced with many challenges when bringing up a child with autism, especially if there is a lack of support, or people do not understand the issue. It can be an overwhelming experience that leads to an increase in parenting stress, marital problems, guilt, shame, conflict (Martinez-Pedraza & Carter, 2009; Torchetti-DPrima, 2018; Zucker et al., 2021), and mental health issue (Caliendo et al., 2020; Kovshoff et al., 2017).

Parents can also find that their child with autism have behaviors that may be embarrassing in public, such as flapping, clapping, or jumping (Caliendo et al., 2020). The more difficulties that parents/caregivers face, the more negatively impacted is the diagnosed child, or any additional other children in the household. It is important for parents to address their own needs, as well as their children.

Siblings may have negative behaviors (i.e., physical aggression, throwing tantrums), a decrease in social skills, and/or a decrease in emotional stability due to parental stress that can be felt by others living in the home (Torchetti-DiPrima, 2018; Zucker et al., 2021). Researchers have also found more behavioral issues and sibling conflict if parents had any form of mental health issues, such as depression or anxiety

(Caliendo et al., 2020; Kovshoff et al., 2017). Increasing support systems for ASD siblings could be a possible solution to decreasing parenting stress and sibling behaviors (Torchetti-DiPrima, 2018; Zucker et al., 2021). The amount of parental stress that comes along with parenting a child with ASD is something for professionals and parents to think about. They should be mindful of how much stress may impact the sibling without disabilities and the entire family.

Siblings

Siblings often receive limited information about their siblings' diagnosis or the cause of many behaviors (Opperman et al., 2003). Open communication between family members can create a healthy opportunity for people to express themselves (Caliendo et al., 2016; Connell et al. 2016). Therefore, services and supports should not just be for the individual with ASD, but siblings, parents, caregivers, and any other pertinent individuals within the immediate family dynamic (Caliendo et al., 2020; Connell et al., 2016; Zucker et al., 2021).

Children's development and comprehension can affect the processing ability for individuals to understand ASD and the impact it may have on their life (Ferraioli, 2009).

At a young age, I (Zara) found I was embarrassed by Eddie but it is difficult to make sense of your feelings when you are 6 years old. I would say going through life with a special brother like Eddie was more difficult as a teenager; however, my close friends were used to Eddie having known him all his life and this helped, but as a teenager I was very conscious of my others' reactions especially my peers. These feelings were more pronounced during outings with Eddie and

mum when difficulties most often arose. He was always up to something whenever it was running away, jumping on someone's motorbike, taking another child's toy or having a tantrum (Connell et al., 2016, p. 50).

Zara may not have understood what was happening when she was 6 years old.

Younger siblings may not understand aggressive behaviors and become fearful of their siblings with ASD behaviors (Ferraioli, 2009). Siblings of children with ASD often observe physical violence, aggression, tantrums, and any other behaviors that their sibling with ASD may exhibit to self, property, or others (Watson et al., 2021). Behaviors associated with ASD can be very unpredictable, so it is understandable why younger siblings may be afraid, confused, or embarrassed.

Younger siblings also may not understand the severity of ASD and what that means for the entire family unit (Connell et al., 2016). They lack a clear understanding of what having autism means. As parents, sometimes we fail to include children on major issues because we feel that they do not understand, or that it may be too overwhelming for such a young person. Often, younger siblings do not want to be more of a burden to their parents, so they tend to try to be very good, help more, or isolate so that they do not further burden their parents (Watson et al., 2021). Some children experience a sense of powerlessness, or guilt, when they observe how their parents, especially mothers, take care of the sibling with ASD (Connell et al., 2016).

Behavior problems of children with ASD have been found to be a predictor of behavior problems in their siblings (Petalas et al., 2012). Increased behavior problems led to increased sibling conflict. Behavior problems, such as physical aggression, increased

defiance, or throwing tantrums, of the child with ASD, also predicted less warmth and more conflict and rivalry in their sibling relationship (Caliendo et al., 2020; Petelas et al., 2012).

Personal and Sibling Identity. The relationship with a sibling with ASD can impact sibling identity (Dumke, 2015). A diagnosis of autism can negatively impact siblings, due to the lack of interactions, social skills, and/or communication that characterize children with ASD. These are powerful components that contribute to ASD siblings and their interactions with one another. Siblings found that the experiences they had with their ASD sibling influenced who they were in their adult life and how they interacted with other people (Dumke, 2015). In particular, how siblings interacted with interpersonal relationships, conflict resolution, emotional stress, self-esteem, and parenting (Howe & Recchia, 2014; O'Brien et al., 2011; Opperman & Alant, 2003).

Adolescence can be more of a challenging time for siblings with a sibling with ASD (Connell et al., 2016; Opperman et al., 2003). This is a period where individuals are more conscious of the opinions of their peers. It is also a period of time where individuals are learning who they are, developing new relationships outside of the family unit, and learning a sense of self (Opperman et al., 2003). Adolescents felt a mixture of emotions about having a sibling with ASD, particularly with interactions between their peers and sibling and their peers witnessing any aggressive behaviors (Chu et al., 2021). They experienced unsurprising feelings of anger, frustration, shame, hurt and embarrassment if subjected to any negative behaviors that their ASD exhibit in the presence of their peers (Watson et al., 2021).

Sibling Relationships

Siblings can have an important influence on one another's development, especially when they serve as social partners, role models, and/or big brothers/sisters to the individual (Mchale, Updegraff & Whiteman 2012). Siblings often spend more time with one another than with anyone else (Soysal, 2016). This "sibling dynamic" affects children in four different ways (Howe & Recchia, 2017). First, sibling interactions are defined by strong, uninhibited emotions of a positive, negative, and sometimes ambivalent quality. These emotional connections can be a source of playmates, watchers, support providers, or annoyance (Soysal, 2016).

Intimacy is an important part of sibling relationships (Howe et al., 2017). As children, they spend large amounts of time playing and interacting with one another. This period of intimacy, usually start when siblings are adolescents (Soysal, 2016). Adolescents is a stage where more individuals seek their own identity, detach themselves from parents, and began to develop friendships/relationships outside of the family. The sibling relationship will either increase, or decrease, at this stage (Howe et al., 2017). Sibling relationships are characterized by large individual differences in the quality of children's relations with one another (Howe et al., 2017). These interactions are an arena for practicing relationship skills (Feinberg et al., 2012). The age difference between siblings often makes the issues of power and control, rivalry and jealousy, and sources of contention for children. However, these also can provide complementary exchanges, such as teaching, helping, and caregiving interactions (Howe et al., 2017).

Sibling relationships can be influences in both positive (i.e., closeness) and/or negative ways (i.e., conflict) (Howe et al., 2017). Healthy sibling relationships are characterized by empathy, prosocial behaviors, and academic achievement (Mchale et al. 2012; Zucker et al., 2021). Healthy sibling relationships are commendable when both parties feel loved and supported. However, unhealthy relationships may be harmful and devastating (Sidhu, 2019). Toxic sibling relationships have been linked to a higher rate of depression, self-harming behavior, psychotic features (Sidhu, 2019), mental health, medical, and stress issues (O'Brien et al., 2011), and externalizing and internalizing issues (McHale et al., 2012). Sibling relationships are important because it can play a larger role into adolescence and adulthood (Cox 2010; Feinberg et al., 2012) and personality development (Mchale et al., 2012). These relationships can also have a significant impact on future relationships (i.e., friends, partners, etc.) (Zucker et al., 2021). Sibling relationships are challenging for typically developing individuals (Sidhu, 2019).

Sibling Relationships When One Sibling Has Autism Spectrum Disorder

Prior researchers on sibling relationships, when at least one of the siblings have ASD, have arrived at inconsistent findings (Angel et al., 2012; Longobardi et al., 2015; Mandelco et al., 2015; River & Stoneman, 2003; Zucker et al., 2021). Some researchers have indicated that siblings report that they love and admire their brother or sister who was diagnosed with ASD (Mandelco et al., 2015; Rivers & Stoneman, 2003;). They care about what happens to their ASD sibling and enjoy when they have positive interactions (Angel et al., 2012). Positive relationships with siblings that have been reported include

warmth, affection, and emotional and practical support (Longobardi et al., 2019, Zucker et al., 2021). When reporting positive relationships with the sibling, they are more likely to have a healthy psychological well-being (Mandelco et al., 2015). Healthy sibling relationships with individuals with ASD are critical since these relationships are related to lifelong development and relationships of both the individual with ASD, and the sibling. Positive and healthy relationships are also key components to a healthy family unit (Zucker et al., 2021). Though there are positive impacts that relationships with siblings with ASD can have, there are also negative ones.

There are individuals who feel that they are not close with their ASD sibling and feel they are a burden because the rest of the family is more focused on the member with ASD (Opperman & Alant, 2003; Plavnick, 2014), or they are made too responsible for the needs of their sibling (Watson et al., 2011). Communication skills and interpersonal relationships can also be hindered due to their sibling having ASD (Mandelco et al., 2015; Zucker et al., 2021). Siblings have a very hard task of building relationships when one of them may be nonverbal and/or have a lack of social skills, behavioral challenges, and not able to understand how to form healthy relationships (American Psychiatric Association, 2013; Mandelco & Webb, 2015). Siblings can also learn dysfunctional behaviors from their sibling with ASD (Plavnick, 2014). For example, an individual can lack communication skills or language skills because they do not experience these types of interactions with their sibling with ASD.

Support systems or support groups are also another way for siblings to openly communicate with other individuals whom they feel share in their experiences (Zucker et

al., 2021). Sibling support groups of children with a variety of medical or mental health impairments, have shown improvements in sibling relationships (Mchale et al., 2012; Zucker et al., 2021). However, ASD siblings who participated in support groups reported less improvement in their relationship with their ASD sibling (Granat et al., 2012). This lack of improvement could be because ASD may be a more challenging issue, or that the group was not specific to ASD.

Lack of communication was also another area that adolescents identify as an area of concern with their sibling with ASD (Chu et al., 2021). Often times, siblings are not involved in any of the communication trainings, support groups, or discussions on how to effectively communicate with their sibling with ASD (Caliendo et al., 2020; Zucker et al., 2021). Communication is one of the major deficits that impact individuals with ASD, so major support should be implemented in this area with siblings (Chu et al., 2021).

Previous Research of Sibling Relationships From Parents' Perspective

Previous researchers who have attempted to study the relationships between individuals with ASD and their siblings, often depend on data collected from parents (Caliendo et al., 2020; Chan, 2016; Latta et al., 2013; Martinez-Pedraza et al., 2009). Data were often limited to mothers, with some input from fathers, counselors, and teachers (Latta et al., 2013). Parents were more often to characterize their child that does not have a disability as having positive and healthier relationships with their sibling with ASD (Chan, 2016; Martinez-Pedraza et al., 2009). Many parents do not want to admit that their children do not get along with one another. Parents think of themselves as a

failure or feel guilty when they must admit that there are problems in their household (Caliendo et al., 2020; Latta et al., 2013).

Some researchers have reported parents who have a child with ASD in their family acknowledge that their child without a disability exhibited mental health issues (Caliendo et al., 2020; Chan, 2016), poor social skills, fewer friends (Caliendo et al., 2021; Zucker et al., 2021), and experienced more behavioral issues. Professionals and parents should be mindful of the siblings' voices and aware of the feelings they may have towards their ASD sibling (Chan, 2016). Sibling concerns should alert professionals, who provide treatment for children with ASD, to assess the needs of the entire family, and not just the individual with ASD.

Support for Family Members of Individuals With Autism Spectrum Disorder

Treatment and Support for Individuals With Autism Spectrum Disorder

Parents of children with autism are faced with many unique challenges, so it is important for them to have a support system. There are informal and formal supports. Informal supports are assistance with everyday tasks or the emotional support that is needed from spouses, partners, immediate family members, extended family members, and friends (Hartley & Schultz, 2015). Formal supports include all the professional involvement including pediatricians, speech-language pathologists, physical and occupational therapists, behavioral therapists, and special education teachers (Caliendo et al., 2020; Hartley & Schultz, 2015). These resources should include communication, education awareness, one-on-one time, interactive skills, safety in the environment, expression of feelings (Wheeler, 2019; Zucker et al., 2021), and an opportunity to have a

normal life (Wheeler, 2019). The importance of parental involvement is one of the key components in supporting healthy sibling relationships into adulthood and should be a strategy for professionals to use (Mailick et al., 2009).

Research shows that women are more likely to enlist the help of formal supports, especially with mental health (Hartley & Schultz, 2015). On the contrary, there are families who may not have access to informal or formal supports due to poverty, lack of transportation, fear, or other extenuating circumstances (Caliendo et al., 2020). The lack of support leads to an increase in parental stress. Increase in treatment and support systems can lead to healthier and more positive relationships.

Support for Siblings of Individuals With Autism Spectrum Disorder

In order to incorporate an SESF that is beneficial, professionals need to understand the impact that ASD relationships have by hearing directly from the sibling. More research and greater clinical evaluation are needed in this area (Pollard et al., 2013). Supported therapeutic interventions should address the sibling relationship quality with individuals with ASD and their typically developing siblings (Pollards et al., 2013; Zucker et al., 2021). These interventions would be beneficial to increase social support within the sibling relationship and help decrease the number of negative interchanges between them.

Professionals should be encouraging brothers, sisters, friends, and/or close relatives to share their experiences about living with an individual with ASD (Caliendo et al., 2020). There should be more open discussions, specifically for siblings to be able to express their emotional, mental health, or physical needs (Connell et al., 2016; Zucker et

al., 2021) in growing up with a sibling with ASD. A sibling with ASD showed a decrease in social efficacy, emotional efficacy, positive affect, and higher negative affect, compared to typically developing siblings (Habelrih et al., 2018). Therefore, hearing shared living experiences would be helpful in developing a clear perspective of individuals who have an ASD sibling, and their lives, particularly from childhood (Habelrih et al., 2018; Tucker, 2017). These concerns will alert professionals who provide services to families with ASD children and siblings (Chan, 2016). Professionals should be assessing the needs of the entire family, and not just the individual with ASD. The challenges siblings may face, in relation to interactions with their siblings with ASD, cannot be ignored (Watson et al., 2021). Research suggests (Habelrih et al., 2018; Watson et al., 2021) that children should be educated on ASD, the meaning of it, and be included in any therapies or treatments and that professionals should recognize the entire family (Connell et al., 2016). ASD is not just an individual diagnosis, it is a diagnosis that impacts the whole family (Connell et al., 2016).

SESF is a therapeutic option that encompasses the whole family (Connell et al., 2016; Kovshoff et al., 2017; Zucker et al. 2021). It involves various support groups and opportunities for siblings to be able to express themselves openly. Based on the SESF option, these shared experiences can provide resources and assist in implementing appropriate family supports (Kovshoff et al., 2011). Parents can also use supportive strategies to help support healthy relationships with siblings of individuals with ASD (Wheeler, 2019). SESF involve support groups, resources, and strategies that are specific to siblings of individuals with ASD. These resources should include communication,

education awareness, one-on-one time, interactive skills, safety in the environment, expression of feelings (Wheeler, 2019; Zucker et al., 2021), and an opportunity to have a normal life (Wheeler, 2019). The importance of parental involvement is one of the key components in supporting healthy sibling relationships into adulthood and should be a strategy for professionals to use (Mailick et al., 2009).

Overall, sibling support groups of children with a variety of medical or mental health impairments, have shown improvements in sibling relationships (Mchale et al., 2012; Zucker et al., 2021). However, ASD siblings who participated in support groups reported less improvement in their relationship with their ASD sibling (Granat et al., 2012). This lack of improvement could be because ASD may be a more challenging issue, or that the group was not specific to ASD. However, for my study, adult siblings' perspective can provide insight on what it was like growing up in a household with an Autistic sibling and a retrospective insight as to what professionals can do to support them. There can be a support group, or resources that is specific for ASD siblings needs. Professionals should be able to determine more effective strategies that support siblings and the adaptations that they should make in living with an ASD person. This study is an opportunity to enlighten professionals to a better understanding of ASD siblings, their interactions, their relationships, and experiences with one another, and how these experiences impact them in adulthood (Habelrih et al., 2018).

Summary and Conclusions

In this chapter, sibling relationships, ASD sibling relationships, parent perspective of ASD relationships, and siblings' perspective on ASD relationships, was discussed.

There are a number of factors that contribute to problems in ASD siblings' relationships. These factors can impact the ASD relationships in positive or negative ways. For instance, ASD siblings may experience psychosocial adjustment issues or a lack of social skills (Caliendo et al., 2020; Zucker et al., 2021), or an increase in love and empathy (Watson et al., 2021; Zucker et al., 2021). However, the majority of these findings are based from the parent's perspective (Khan, 2016; Latta et al., 2013), and limited to online data collection (Pollard et al., 2013). The discrepancy in the information presented clearly highlights some of the reasons why studying ASD relationships would be important.

Research suggest that professionals should take a *family centered* approach when addressing ASD siblings since interrelationships are very important (Petalas et al., 2012), also known as the SESF approach. Psychological assessments should start supporting family focus interventions, by considering the interconnectedness of family subsystems. SESF focuses on understanding siblings' experiences and how these experiences impact their relationships with different family members (Kovshoff et al. 2017). SESF is an effort to help improve sibling dynamics, relationships, but overall, the well-being of all children who live in a household with an ASD person (Kovshoff et al., 2017). The therapeutic option is specific to my research, which focuses on individual experiences growing up in a household with an ASD sibling.

Interviewing ASD siblings would be the most beneficial way to shed light on their own experiences and concerns and the impact that ASD has had on their adult life (Chan, 2016). In using a qualitative phenomenological approach, I investigated young adults and their retrospective perspective on growing up in a household with an ASD sibling, which

may help bridge the gap with current research. Upon exploring all the research, it was evident that more research was needed to better understand real life stories and experiences of individuals who grew up in a household with an ASD sibling. Perspectives on young adults, ranging in age from 18-25, are severely lacking in the research produced so far. The young adult age is a stage in life where most individuals are asserting their independence (Connell et al., 2016; Chu et al., 2021; Opperman et al., 2003). Their viewpoints, or perspectives, may differ when they are at a different developmental stage of life. Future research should be investigated with young adults answering their own questionnaires, surveys, and identifying their own feelings about the ASD sibling versus the parent. In my study, I used the phenomenological research design to study lived experiences with ASD siblings, which can be answered through real conversations.

Before beginning the interview process, I first addressed the issues of trustworthiness. Hearing personal stories and lived experiences from siblings may provide more content and concrete evidence of what it is like growing up in a household with an ASD sibling. However, these topics are very personal and people may not trust me to disclose such personal information. In Chapter 3, I will discuss more about the two tools that were used to increase trustworthiness: reliability and validity. Reliability and validity are the responsibility of the researcher on reporting accurate and credible information on what the participant is saying (Cypress, 2017). Also, an overview of the phenomenological qualitative approach, will be addressed in Chapter 3.

Chapter 3: Research Methods

Introduction

The purpose of this phenomenological qualitative study was to explore siblings' lived experiences growing up in a household with a sibling with ASD. My goal was to speak directly to individuals who grew up in a family where one of their siblings was diagnosed with ASD about their lived experiences to provide a better understanding of this issue from their perspective. The potential contribution may be the generation of information that could improve professionals' understanding of how-to best support siblings of individuals with ASD. This understanding may be beneficial to professionals in devising early therapeutic interventions if sibling crisis situations arise. In this chapter, I discuss the research design and rationale, role of the researcher, methodology, issues of trustworthiness, and ethical procedures.

Research Design and Rationale

I sought to answer the following research question: What are siblings' lived experiences in growing up in a household with a sibling with ASD? A phenomenological qualitative study was the most appropriate because I sought to explain a phenomenon, something that necessitates a telling of personal experiences related to specific situations (Chan, 2016; Stake, 2010). Phenomenology is a way for researchers to capture authentic and real lived experiences (Moustakas, 1993), through observations of people or events that are pertinent to the person (Valentine et al., 2018).

Phenomenological research is more intimate than other types of qualitative research. It focuses on the firsthand experiences of the participants and allows them to

share these experiences through interviews (Christensen, 2017; Creely, 2018); Neubauer et al., 2019). A weakness of using the phenomenological approach is that the results are based on the quality of the interview answers provided by the participants and the interpretive skills of the researcher (Tuffour, 2017). There is also the limited ability to generalize the results of the study to others outside of the group of participants. The individual is reporting information that is based on their own personal experiences, so these findings cannot be attributed to others.

I considered other qualitative approaches but concluded that they were not appropriate for my study. One approach, ethnography, originated in social and cultural anthropology and features the researcher's direct involvement in the environment being studied (Chan, 2016; Harrison, 2018). In this study, I was not directly involved in the environment being studied. A strength of the ethnographic approach is that data is used to compare and contrast accounts of awareness, actions, behaviors and events, through the eyes of individuals directly impacted by that environment (Tenny et al., 2021). The weakness is that this approach is very time-consuming (Chan, 2016) and it is based on one particular setting (Tenney et al., 2021). This design was not appropriate for my study because I wanted to examine young adults' perceptions of their ASD sibling in all settings (i.e., school, community, etc.).

The case study approach is focused on a specific subject, such as a single person, group, place, event, or organization (Piper et al., 2021; Simons, 2009). The advantage of a case study is that the researcher can develop an understanding of complex issues in real-life contexts by delving into the life and experiences of the individual or subject

being studied (McCombes, 2020). The disadvantage is that researchers cannot see everything that is going on and that observation or interpretation bias can occur (McCombes, 2020; Piper et al., 2021). I also did not want to limit my research to only one individual or family. I believed that it was better to speak to multiple individuals because my study was more exploratory in nature and because it could lead to recommendations for future research and application of results.

Role of the Researcher

My role was to be an observer/participant throughout the research process and to conduct my research with integrity and honesty. I am a licensed social worker who is responsible for individual, group, and family therapy and have been acting in this role for 18 years. I did not have any professional or personal relationships with my study participants as this would present a conflict of interest and have the potential to increase research bias (Weatherford & Maitra, 2019).

Because I am a professional in the field, I limited any personal biases or influences by using bracketing. Bracketing is a way for the researcher to separate their own experiences, attitudes, and biases from what is being studied (Weatherford & Maitra, 2019). Bracketing meant that I refrained from engaging in any judgment while conducting my interviews and was mindful of any potential biases that might interfere with my interpretation of the data.

To reduce any potential biases, I took field notes related to thoughts and judgments I found myself having any emotions I was experiencing throughout the data collection, coding, and interpreting phases of my study. Field notes are highly

recommended for qualitative research since it can be used as evidence and documentation of contextual information (Phillippi & Lauderdale, 2017). It was also very important for me to be mindful of nonverbal behaviors, such as facial expressions and body gestures (Fink, 2000). Prior to beginning my research, the participant selection process was very important.

Methodology

Participant Selection Logic

Population refers to a group of individuals who may be defined by different characteristics or attributes (i.e., favorite color; team, etc.; Banerjee et al., 2010). In my study, the population included how many families had at least one child with ASD. According to the Centers for Disease Control and Prevention (2022), approximately 1 out of 100 children are diagnosed with ASD.

I utilized purposeful sampling, as well as snowball sampling for my study. Purposive sampling is a qualitative measurement that helps select respondents that are most representative of one's research topic (Ames et al., 2019). Purpose sampling is mainly used when selecting individuals based on the phenomenon of interest (Palinkas et al., 2015). Snowball sampling is a method used by researchers through referrals made by individuals who share a particular interest with the target population (Kirchherr & Charles, 2018). My sample size consisted of six people from the selected target population. Sample size is a small portion of people who were chosen from the target population (Banerjee et al., 2010).

The inclusion criteria for the study were that participants be between 18 and 25 years of age. Young adults, ages 18-25, are the only age group to be used since this is the closest developmental stage when most individuals are asserting their independence and leaving their parents household (Scales et al., 2016). The young adult phase is a time of reflection when most individuals are beginning to reflect on their childhood, extended educational choices, career choices, whether they want to have children, and/or other major decisions in their life (Hamama et al., 2021).

- Grew up in a household with a sibling who was diagnosed with ASD.
- Are no longer living in the home with their parents and sibling with ASD.
- Read, speak, and understand English.
- Any individual who did not meet all of these inclusion criteria were excluded from participating in this study.

I recruited nationwide through the use of social media. I posted my recruitment materials (see Appendix A) on the Walden University Participant pool, Facebook, and Instagram. The Facebook and Instagram groups that I posted my materials (see Table 1), did not need permission to join or post in these groups. I also asked the Walden University Institutional Review Board (IRB) to have inclusion of my study in the Walden University Pool as part of the IRB approval process.

Table 1

Facebook and Instagram Groups Used for Participant Recruitment

Social media platform	Group
Facebook	Spectrum of Possibilities Support Group Autistic Older Adults Support Group Autism on the Network Support Group

Instagram

Autism Moms Support Group
 Autism Support and Awareness
 The Help Group
 Autism Speaks

The participants were asked to respond to prescreening questions (see Appendix B) via email or phone (depending on how they contacted me) to determine participant eligibility. If they answered “yes” to each inclusion question, an email was sent with the informed consent document attached, as well as dates/times that I was available to interview them. Participants were asked to respond with “I consent” if they wished to continue in the study as well as indicate what interview time worked best for them. When I received this information, I emailed them a confirmation of the interview date and time as well as a link to the Zoom interview session. I also requested that they planned to interview in a room with no other distractions and where others could not overhear the contents of the interview.

Instrumentation

Demographic information that was included in my study were the following: age, gender, race, ethnicity, geographical area, marital status, and educational level.

Demographic information made it possible to describe the characteristics of the sample population (Casteel et al., 2021). Table 2 shows four demographic questions and their corresponding response options.

Table 2

Demographic Questions

Question	Response choice
1. What is your age?	Age in years

2. What is your gender?	Male Female, Other Prefer not to answer
3. What is your race?	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Two or prefer not to answer more races
4. What is your marital status?	Single Married Divorced Widowed

I utilized semi structured interviews for my study. The questions were developed based on the review of the literature. I also developed prompts for each of the questions to help obtain clarification or additional information if needed. The interview questions and prompts are shown in Table 3.

Table 3

Interview Questions and Prompts

Interview question	Prompt
1. How many siblings do you have?	
2. Where do you fit in birth order with your siblings?	Tell me more about how your birth order made you feel?
3. Thinking back to your children, how would you describe a typical day with you and your siblings?	Tell me more about that
4. Tell me some childhood memories that stand out with you and your sibling with ASD?	Any other memories that you have that you want to discuss?
5. How old were you when you found out that your sibling had ASD?	Is there a particular memory that is associated with that?
6. What was your understanding of what autism was when your sibling was diagnosed?	Did your understanding change over time?

- | | |
|--|--|
| 7. What was it like growing up in a household with a sibling with autism? | Do you have any special memories to share? |
| 8. What would you wish your parents would have known about what it was like for you when you were growing up in relation to living with a sibling with autism? | Tell me more about that. |
| 9. If you had to give any advice to professionals about growing up in a household with an ASD sibling, what would it be? | How could that advice have helped you when you were a child? |
-

Procedures for Recruitment, Participation, and Data Collection

I sought approval from the IRB at Walden University. Once approval was given, I posted an ad to social media. The interviews took place via Zoom. At the beginning of each interview, I asked the participant if I could start the recording. If they indicated yes, I started the recording. The interviews were recorded using the Zoom voice recording app located on the Zoom website. I only record the verbal portion of the interviews and did not use or record video.

I reminded participants of the contents for my research study and inform the interviewees that I would be taking field notes throughout the entire interview process. For instance, I showed the participants my pen and paper and explained if I was looking down a couple times, it was just for note taking. I followed the interview protocol that can be found in Appendix D. The interview protocol first included some icebreaker conversations to build rapport with the participant. Building rapport and having comfort is a significant component when talking to participants (McGrath et al., 2019). Rapport building should begin the moment the participant responds to the ad and continue throughout the entire interview process.

After explaining to the participant that I would be taken notes throughout the duration of the interview process, I then asked the participant if they had any questions about the study, the informed consent, or the interview process. I answered any questions that they had. I also reminded the participants that they could stop participation at any time. If they did not wish to be recorded, or indicated they no longer wanted to participate at any time during the interview, I would have stopped the interview, thank them for their time, and ended the interview. If anyone indicated that they would no longer want to participate in my study, I would not use any data from their interview in my study.

After answering any questions, I asked the participant the demographic questions using the prompts as needed (see Table 2 and Appendix B). Once demographic questions were completed, I asked all the interview questions (see Table 3 and Appendix C). I used the prompts indicated as needed to glean further information and clarification from the participant.

Once I completed the interview questions, I informed the participant that I was ending the recording. Once communication was given that the recording was completed, I informed the participant that I would be transcribing the interview and sending them a copy of the transcription for their review to ensure accuracy. I let them know that they had 7 days after the receipt of the transcript to let me know about any inaccuracies with the interview information or if they would like any information redacted.

Transcription was completed using the Evernote App (www.evernote.com). After transcription was completed using the Evernote App, I listened to the interview recording, while reading the transcript, to ensure that the transcription was correct and

made any corrections as needed. I then sent the transcript to the participants via email and reminded them to respond within 7 days if they noted any inaccuracies in the transcript. Once that time was passed, I began analysis of the data.

Data Analysis Plan

I used the coding style from Saldaña (2021). The steps involved in this data analysis style included two cycles of coding:

1. Manual hand written notes: These manual hard written notes allowed me to code by highlighting or circling any key terms that arose. Saldaña (2021) refers to this stage as first cycle coding. First cycle coding is the initial coding of finding any repetitive patterns, themes, or terms in the data.
2. Reorganization: I reorganized and condensed the initial coding patterns into more specific categories, also known as second coding. Second coding focuses on grouping patterns into a smaller number of sets. For instance, if a participant says, “I was scared of my ASD sibling”. I would label “scared” as a code. After naming my codes, I organized my data into categories to see if there were any presenting themes.

Issues of Trustworthiness

Trustworthiness is important for any researcher. It means the degree of confidence in data, interpretation, and methods used to ensure the quality of the study (Adler, 2022). Trustworthiness was key for me to ensure credibility, transferability, dependability, and confirmability.

Credibility

One way to ensure credibility is to make sure that there are no research biases or stereotypes (Adler, 2022). As a researcher, I had to make sure that the research was being interpreted in an unbiased way. Coding is a significant factor in helping to interpret the research without any biases and ensuring credibility. In order to be credible, I will also ensure that all data will be made available for 5 years. After 5 years, all data will be disposed of through the use of shredding and deleting files from my computer database.

Credibility can also be established through “member checking”. McSweeney (2021) explained that member checking, also known as member validation, is when the participant gets to explore the credibility of the results. Member checking gives participants the ability to validate any of the interpreted data, prior to any submissions. Member checking also helps with reliability of the study. Reliability is the likelihood of a study being able to be repeated, or replicated (Cypress, 2017). In qualitative research, human behavior cannot be predicted or replicated; however, it is important for the researcher to keep their role and questioning the same.

Transferability

Trustworthiness can also be established by being honest and transparent on the purpose of the research study (Adler, 2022). This transparency is called transferability. It was important to provide the interviewee with evidence that my research studies findings can be useful and applied to other contexts. In my study, siblings could help give insight on the impact that ASD has had on their life from childhood to adulthood. In order to

avoid any transferability concerns, I made sure that my findings were not generalized to the entire population of ASD individuals.

Dependability

Dependability refers to the stability of the researcher and minimizing any biases that may arise (McSweeney, 2021). There are three different types of biases in qualitative designs (Enago Academy, 2019). First, is interview bias. Biases occur when the interviewer can subconsciously influence the way a person responds just by body language, tone, eye contact, or other nonverbal cues. Second, is response bias. For instance, a person may answer a question based on how they feel the researcher may want them to answer it. Third, is reporting bias, which means reporting the positive or more exciting results. People are more likely to report things that are good versus bad. To avoid bias, I did the following, per Kornbluh (2015):

- Read each question exactly how it appeared.
- Did not interpret the question for the interviewee.
- Offered to repeat the question exactly how it appeared.

Setting clear boundaries and rules is a key factor in decreasing interview, response, and reporting biases (Kornbluh, 2015).

Confirmability

Another key component to ensure trustworthiness is confirmability, which refers to the degree the results can be confirmed by the participants (Adler, 2022). To establish confirmability in my study, I explained to interviewees that I would be using an audio tape recording to capture the interviews and utilizing hand written notes to hold myself

accountable. Hand written notes were used to manually code themes that surfaced during the interview process. Just like credibility, member checking can also be used to establish confirmability. While establishing trustworthiness of my research, I also made sure that I was following all ethical procedures.

Ethical Procedures

I completed human subjects research training per Walden University IRB requirements (see Appendix D). I did not recruit or conduct any interviews until I received IRB approval (no. 08-16-22-0054093). The informed consent form was sent to individuals who contact me about participating in the study, via email. Then, they were asked to review the informed consent and reply to the email with the words “I consent” if they consented to participate. No incentives were offered to participants.

Recordings, transcripts, and coding files have been secured on a password protected computer. The only individuals with access to the raw data were myself, my committee members, and members of the IRB, if requested. All participants were at least 18 years of age. It was very important for me to ensure that I was not inflicting any psychological harm or distress to participants, which is called mitigating (Stahike, 2018). Therefore, the actual names of the participants were kept separate from the interview transcripts and numbers were assigned to the participants. I did not provide any information that may identify a particular participant. I also reported demographics of the sample in aggregate to not identify participants. I will keep the raw and coded data for 5 years after CAO approval of the study and then destroy the data per Walden University

IRB requirements. All materials have been stored away in a safe storage unit located in my home.

Summary

The primary goal of Chapter 3 was to outline the research method used to answer the research question. A detailed explanation of the procedure, participant sample, data collection, prescreening questions, interview questions, and ethical considerations, were given. A phenomenological methodology approach was used to understand individual's perceptions in living in a household with an ASD sibling from a retrospect perspective. All participants may contribute to this study by giving their personal experiences of what it is like growing up in a household with an ASD sibling. In Chapter 4, I provided the study's findings and demonstrate how the methodology was followed.

Chapter 4: Results

Introduction

The purpose of this phenomenological qualitative study was to explore siblings' lived experiences while growing up in a household with a sibling with ASD. I interviewed individuals who had grown up in a family where one of their siblings was diagnosed with ASD about their lived experiences. My goal was to gain a better understanding of this issue from their perspective. In this chapter, I discuss the research setting, participant demographics, data collection, data analysis, evidence of trustworthiness, and results.

Setting

I completed all six semi structured interviews using the online videoconferencing platform Zoom (<https://zoom.us>). During each interview, I was located in an enclosed home office space. I sat in front of an off-white background and had a headset on throughout the duration of each entire interview. The space did not have any windows, so there were no known lighting issues that affected the interview process. All interviews were completed in the same way.

Demographics

I elicited the following demographic information from participants: their age, gender, race, ethnicity, geographical area, marital status, and educational level, as presented in Table 4. For confidentiality purposes, I have used numbers to represent the participants. The sample size consisted of seven participants; however, one participant

revoked their consent after the interview process was completed. More details about the seventh participant will be provided in the Data Collection section of this chapter.

Table 4

Participant Demographics

Participant	Age	Gender	Race	Marital status
1	19	Female	Latina	Single
2	23	Female	Hispanic/White	Married
3	21	Female	Hispanic/White	Single
4	24	Female	White	Single
5	25	Female	White	Single
6	25	Male	White	Single

The inclusion criteria for participants included the following:

- between 18 and 25 years of age
- grew up in a household with a sibling who was diagnosed with ASD
- no longer living in the home with their parents and sibling with ASD
- read, speak, and understand English

Any individual who did not meet all inclusion criteria was excluded from participating in the study.

Data Collection

The sample for this study consisted of seven participants, all of whom were interviewed via Zoom. I recruited all participants through social media and snowball sampling. Snowball sampling involves referrals made by individuals who share a particular interest with the target population (Kirchherr & Charles, 2018). I posted an advertisement for the study on the Walden University Participant Pool and on Facebook and Instagram autism support and sibling groups beginning in August 2022; however,

due to inclusion criteria, the first interview did not take place until November 26, 2022. The last interview was conducted April 9, 2023.

I recorded the interviews using the Zoom voice recording app located on the Zoom website. Once the interviews were completed, the audio recordings were transcribed through the Evernote app (<https://evernote.com>). I sent the transcript to the participants via email and asked them to respond within 7 days to note to note any inaccuracies or if they would like any information redacted. One participant responded during this time frame, asking not to have any information disclosed; the participant explained, “I did not realize how much this still bothers me.” I emailed the participant back and asked if there was anything that I could do to be of support for the situation. I also resent the consent form to the participant, which provided the number for Walden University’s research participant advocate. However, the participant never responded to my follow-up email. Therefore, there was no data reported on this participant and data analysis was only presented on the six remaining participants.

Data Analysis

Upon completion of my interviews, I used Saldaña’s (2021) two-step coding style to analyze the research data. This coding style consisted of manual hand written notes and reorganization. The first step of the coding process consisted of manual hand written notes, which I took during the interview process. Taking notes during the interview, allowed me to highlight categories that arose during the conversation. Initial coding of the collected data depicted the following categories: communication, stress, support systems, feelings, and responsibility. The categories that arose from the first level of

coding are the highlighted details of how siblings experienced their childhood in growing up with an individual with ASD. Once these categories were identified (i.e., communication, stress, support systems, feelings, and responsibility), I began the second coding process. Second coding is the process of reorganizing and condensing the initial categories (i.e., communication, stress, support systems, feelings, and responsibility), into more specific themes (Saldaña, 2021; see Table 5).

Table 5

First- and Second-Cycle Coding, Categories, and Resulting Themes

Theme	Category	Code
1. Agreement that communication is a barrier	Communication	Nonverbal
2. Communication issues, behaviors, and sibling stress due to basic needs not being met	Stress	Interactions and difficult Sibling
3. Lack of support from professionals	Support systems	Parental Aides
4. The impact of feelings on the sibling relationship	Feelings	Therapists Caregivers Resentment
5. Too much responsibility and feelings of growing up early	Responsibility	Scared Happy Sibling
		Parent Mother

In the Results section, I provide more detail regarding the specific themes that were found through the coding process.

Evidence of Trustworthiness

I was able to gather details and information from the participants, especially when discussing communication issues, stress, support systems, feelings, and responsibility because the amount of time that was taken on rapport building and to establish trust.

Trustworthiness is comprised of the following five components: credibility, transferability, dependability, and confirmability.

Credibility

Credibility was established through “member checking”. Member checking gave the participants the opportunity to validate any of the interpreted data, prior to any submissions. (Chang, 2014). For instance, participants were able to review the interview transcription after 7 days to let me know about any inaccuracies with the interview information or if they would like any information redacted. Coding is also a significant factor in helping to interpret the research without any biases and ensuring credibility. In addition to coding, storage of the data is another way to ensure credibility (Chang, 2014). To answer any question, or research findings, and allow other researcher to reanalyze the results, I will keep all records for 5 years. All data will be disposed after 5 years, which includes any records and hand written notes. My hand written notes will be shredded and the voice recordings will be permanently deleted from my computer.

Transferability

Trustworthiness can also be established by being honest and transparent on the purpose of the research study (Adler, 2022; Burchett et al., 2013). This transparency is called transferability. It is important to provide the interviewee with evidence that my

research studies findings can be useful and a potential contribution to social change with professionals. Siblings can help give insight on the impact that ASD has had on their lived experiences. In order to avoid any transferability concerns, I will make sure that my findings are not generalized to the entire population of ASD individuals.

Dependability

Dependability refers to the stability of the researcher to minimizing any biases that may arise (Elo et al., 2014). I took measures outlined in the literature to minimize the potential for researcher bias (Kornbluh, 2015; Stahl & King, 2020). The strategies were as follows:

- Read each question exactly how it appears.
- Did not interpret the question for the interviewee.
- Offered to repeat the question exactly how it appeared.

In two interviews, participants (Participant 1 and Participant 4) asked me to clarify what “professionals” meant in Interview Question 9 (“If you had to give any advice to professionals about growing up in a household with an ASD sibling, what would it be?”) I gave examples of different professionals (mental health, doctors, or therapists).

Confirmability

Confirmability is when data is checked and rechecked throughout data collection and analysis to ensure results can be replicated by others (Burchett et al., 2013; Elo et al., 2014). To establish confirmability in my study, I explained to all six interviewees that I would use an audio tape recording to capture the interviews and utilizing hand written notes for accountability purposes. For example, for all interviews, I showed the

participants the notebook that I was using to take notes and I informed them when I would be starting and stopping the audio recording. Hand written notes were used to manually code themes that surfaced during the interview process. Just like credibility, member checking was also used to establish confirmability.

Results

The research question for the study was, What are siblings lived experiences in growing up in a household with a sibling with ASD? Based on the shared responses from the 6 volunteers who participated in the study, I identified five key themes that determined a sibling's lived experience in growing up in a household with a sibling with ASD: communication, stress, support systems, feelings, and responsibility

Theme 1: Agreement That Communication Is a Barrier

In my research, all six participants discussed how they lacked in communication with their sibling who was diagnosed with ASD. According to Habelrih et al. (2018), a sibling diagnosed with ASD can show deficits in social efficacy, emotional efficacy, positive affect, communication skills, and interactions with others. Siblings both expressed concerns over communication and interactions with their ASD sibling and wished these areas were better. As a part of the second coding process, two specific codes arose from the main category communication: nonverbal communication and interactions and difficult communication.

Nonverbal Communication

According to the *DSM-5* (American Psychiatric Association, 2013), nonverbal communication means eye contact, facial expressions, body language or understanding

the use of gestures. When describing her brother's nonverbal communication, Participant 3 said, "he would just point to things, or I would just know what he needed. For a while that was the only way he was able to communicate with us." Participant 4 said,

In the same way that I love spending time with him doing things with him, I can't communicate with him. I have to use other ways to read other cues from him as the main way that I get to know him. And that makes it very difficult.

Participant 6 expressed, "I primarily just thought of him as being different in the sense of he wasn't really verbal." If there is difficulty in people understanding nonverbal cues in others, there is a higher chance that one would have difficulty with communication and interactions with others, specifically when diagnosed with ASD (Hodges et al., 2020).

Interactions and Difficult Communication

Five siblings expressed that communication is still an area in which they struggle with their ASD sibling, even as young adults. They used the word "difficult" when describing trying to communicate. It continues to limit the "interactions I have with my sibling" Participant 4 stated. Participant 5 explained there were times that they just did not interact with their sibling because they did not know how to communicate with them at all. Participant 6 said that interactions were very difficult, so many times he would just communicate with his sibling's aide.

Communication issues can be the source of challenges for many people with romantic relationships, workplace cultures, colleagues, team building, and many other areas. Lack of communication has been a significant area that adolescents have identified

concerning their siblings with ASD (Chu et al., 2021) because it limits the amount of interaction they have with their sibling. In my study, communication issues negatively (i.e., barriers, difficult interactions) impacted sibling relationships. Siblings described how nonverbal behaviors became their only source of communication in how to interact with their ASD sibling, which was still very difficult because they did not truly understand what their sibling may or may not have wanted. When siblings discussed the impact that lack of communication had on their life, their parents' life, and other siblings' lives (not the one diagnosed with ASD), they talked of the amount of stress in the household. Participant 6 said,

When he would run away initially, from what I remember is that my parents would sort of like panic usually. So, me and my siblings would kind of just be hanging around the house waiting for him to come back. It was a lot.

The study revealed that all participants felt that there were communication issues with trying to interact with their sibling who was diagnosed with ASD, which created additional stressors. In my study, communication issues, behaviors, and needs not being met contributing to a stressful environment, was discussed.

Theme 2: Communication Issues, Behaviors, and Sibling Stress Due to Basic Needs Not Being Met

Stress was a key factor when siblings discussed growing up in a household with an individual diagnosed with ASD. For the second coding process, two specific themes about stress were identified: parental stress and sibling stress.

Parental Stress

The study revealed that all six participants felt and witnessed the amount of stress their parents were under. Siblings view on parental stress was a major component in participants lived experiences in growing up with a sibling with ASD. It can be an overwhelming experience raising a child with ASD. Participant 6 said, “it takes a lot of time for them to because they have to focus so much on, it's like, he needs extra attention.” Participant 3 said,

I would say in my adult life, it's shifted less from a focus on how it's affected me as his younger brother, and more so on how it affects my parents because throughout childhood, I kind of saw my mom really having this tremendous task of like getting Billy Bob into the right schooling and in terms of finding him a good home and people to take care of him while he was living with us.

Participant 4 talked about the amount of time that was needed to help take care of her sibling, saying, “it takes a lot of time for them (parents) because they have to focus so much on him, he needs extra attention.” Similarly, Participant 2 stated, “My parents were just so tired and didn't know what to do anymore and had to call authorities for help. The stress was insurmountable.”

Sibling Stress

In addition to parental stress, siblings talked about the stress they experienced growing up in a household with a sibling with ASD. Siblings talked about the impact that ASD had on their lives, their friends, their schooling, and in the community. One sibling, Participant 6 described staying away from the home most days just because of

“interesting things” that were going on in the household. He referred to interesting things as his sibling diagnosed with ASD having issues with running away, screaming, putting holes in the wall, and watching his parents try to handle it all. He said, “around middle school, I would basically be spending most of the day at school, doing some type of after school activity. So, I wouldn't really see my siblings until kind of later in the afternoon, or towards the evening.” Participant 3 talked about how stressful it would be for her to be in the community or at events with her sibling diagnosed with ASD. She expressed that there were many times when their family just had to leave if it was too much for her sibling diagnosed with ASD:

I don't know what the word would be but we were very cautious with kind of anything that we did because we didn't want to...we wanted to make sure that he wouldn't be overwhelmed so we were always just kind of like sticking together especially in like functions or something like that. Once he was kind of done with it; it was too much, we would leave.

Similarly, Participant 6 talked about being responsible for her older brother, helping to clean up feces, change diapers, and doing laundry at a very young age, stating “It was a lot, here I am a little kid, but I wanted to help my parents.”

Family stress can occur in households, especially when there are contributing factors, such as behaviors, aggression, lack of communication, and other issues that siblings have expressed. In my study, siblings expressed that growing up in a household with a sibling diagnosed with ASD was a factor of stress for their parents and for them. With the high amount of parent and sibling stress in the household, siblings discussed the

roles of support systems in their upbringing. Professionals lack of support to siblings is my third theme that will be addressed.

Theme 3: Lack of Support From Professionals

During the second coding process, lack of sibling support, from professionals, was identified as a theme. This lack of professional support was specific to aides, therapists, and caregivers. All siblings said that support systems were there specifically to work with the individual diagnosed with ASD.

Aides

Participant 6 said, “there was usually an aide there when I would interact with John Doe.” Participant 4 said that there were times when she would just want to connect with her brother and spend time with him, but there was always someone around. She gave an example of trying to color and just getting frustrated because the aide would always tell her what her brother wanted.

Therapists

Participant 3 remembered “having therapists come over to the house or I have to go to a center with my family and we would watch him do... I can’t remember what it is called but it is a very hands-on therapy and we kind of just watched him play.” Participant 2 said that there were so many “bad” therapists that just did not get it. They were not in the home, or could understand, what anyone was going through they would just give more work to their parents. Participant 2 said, “as if my parents weren’t going through enough and therapists want to give more work.”

Caregivers

Participant 3 recalled, “caregivers being there to help watch me and my other sister, just so that my parents could deal with my brother.” Participant 6 said that so many caregivers came and gone that he did not remember the names of any of them. He just came to an understanding that there would always be an extra person at the table.

In most families, having an ASD diagnosis means professional involvement, which may include behavior specialist, caregiver support, nurses, communication specialist, respite care, therapy, and many other support systems. In my study, when siblings reflected on their childhood experiences, they all recalled memories of therapists, aids, caregivers, parental involvement, or other professionals involved with the sibling diagnosed with ASD. None of the siblings reported professionals helping at all with sibling interactions. Participant 6 (2023) said, “though the aid was there, it’s not like they did anything. I sat there to play with my brother and they watched.”

Though the participants I had interviewed had support systems (aides, therapists, and caregivers) while growing up in their household, research shows that there are many families that may not have access to resources, particularly families with individuals with ASD (Ming, 2019). Ming (2019) explained that there is an uneven distribution of resources in the United States for families with ASD, which results in long waitlists for diagnostic and therapeutic services, particularly families in rural areas. In understanding that there is a lack of resources for the ASD community, it was important for me to hear the needs of the siblings, especially because they all experienced a range of feelings related to growing up in a household with an individual with ASD.

Theme 4: The Impact of Feelings on the Sibling Relationship

The impact that siblings' feelings had on their relationship with their ASD sibling was the fourth theme. Feelings was very important to my research since the emotional well-being of siblings can be negatively impacted when discussing a child with autism (Hodges et al., 2020). During the second coding process, three codes were identified under the feelings category and now these feelings impacted the sibling relationship.

They were as follows:

Resentment

Participant 3 talked about the resentment she had towards her brother just from his behaviors. She mentioned that she even held that resentment against her sibling with ASD because of how many times that her plans had to be interrupted due to his actions. Participant 6 talked about resenting some of the caregivers in the institutions that “made my brother worst.” She said that the remedy for any behaviors was to put her brother on antipsychotic medicine and the medicine just made it worst.

Fear

Participant 4 talked about being fearful of her older brother. She said she did not understand what was going on and why he would put holes in the wall, destroy things, or yell so much. “He'd been in the middle of a tantrum, and he'd be making all these noises and throwing himself on the ground and punching walls. That was scary.” Participant 6 said that she was more fearful of what her older brother would do to her mother. She said there were times where the cops had to be called from just how violent her brother became.

Happy

Five out of six siblings expressed negative feelings towards the sibling diagnosed with ASD, however, there was one sibling who talked about being happy. Participant 1 admits that there were some challenging times growing up with her sibling who was diagnosed with ASD, but summarized everything as being “happy”. “I was such a happy kid. I still am. Like I, I love my family. I wouldn't have wanted anything different. I'm grateful she (mom) knows that I'm a happy camper.”

Growing up with a sibling diagnosed with ASD brought on feelings of resentment, fearfulness, and happiness. In detail, siblings were able to describe how much these feelings impacted their childhood, and recalled specific memories to explain their feelings. All siblings said that the aids, therapists, and caregivers, would have had a better understanding of the sibling, identified with ASD, if they would have just talked to them. With the varying feelings towards their sibling with ASD, siblings also discussed the amount of responsibility they experienced while growing up.

Theme 5: Too Much Responsibility and Feelings of Growing Up Early

Siblings discussed that there is a lot of responsibility involved in growing up in a household with an individual with ASD. In fact, most siblings said that the responsibility really forced them to grow up early. Responsibility was broken up into three different areas: sibling responsibility, parent responsibility, and mother responsibility.

Sibling Responsibility

Three participants discussed how they were responsible for taking care of their sibling who was diagnosed with ASD. For instance, Participant 2 said, “there would be

poop everywhere and my parents would ask me to either help wash up my brother, or clean the poop up. It was a family affair.” Similarly, Participant 1 said that she was responsible for nighttime routine with her brother who was diagnosed with ASD. She would make sure that her brother brushed his teeth at night and got into bed, so her mother could help with her other siblings and getting them into bed. The three participants agreed that sometimes they did not want to help with certain responsibilities, but still helped because they knew it would be more responsibility on their parent (s).

Parent Responsibility

Parents have overwhelming responsibilities when raising children, especially when there may be other challenges, such as ASD (Habelrih et al., 2018). In my study, all participants could recall detailed memories of their parents’ responsibilities in taking care of their sibling with ASD.

Participant 4 said,

My parents...we would spend the day with him and it's a lot of like, you know, when we'd go to restaurants, my parents have to order the food for him. And they have to, because he often would over eat with his food. The medication causes him to eat a lot. They would have to cut up all the food and like be extra on top of him. And I just I remember all the extra steps that had to be taken with my brother.

Participant 3 described the amount of responsibility that her parents had just to make sure they had a sensory oriented household.

My parents got him everything that they could think of that he really enjoyed like those cocoon swings, we had like a swing, we had all those swings in the basement. We had a huge playground that they put a whole bunch of sensory...foams all over where he would play. We got a trampoline; my dad built him a pool because they found out that swimming was like definitely a way to calm him down and help him sensory wise. So, it was just a very like sensory friendly household.

Mother Responsibility

In addition to sibling and parent responsibility, two participants discussed how much responsibility they observed with their mothers while growing up in a household with a sibling diagnosed with ASD. Participant 6 said he saw how hard his mother worked trying to get help for his brother who was diagnosed with ASD. Participant 5 said they watched how hard their mother worked to show attention to “the both of us, she tried very very hard to make sure we got equal attention.”

Participants observed and recalled many situations while growing up in a household with an individual with ASD. These observations had a significant impact in the area of communication, stress, support systems, feelings, and responsibility. Rapport building was a key component on attaining a lot of information from the participants and gaining their trust. Initially, I utilized some ice breaker conversations and small talk with the participants. For instance, I asked the participants how there day was going and/or if they had to pick a color to represent them, what color would that be? Rapport building began the moment all of my participants responded to the ads in just thanking them for

responding and appreciating them for taking time out of their busy schedules to participate. It helps elicit trust with the researcher/participant interaction. (McGrath et al., 2019). Building rapport and having comfort is a significant component when talking to participant.

Based on the five themes that siblings described from lived experiences in growing up in a household with a sibling with ASD, they also advised professionals about the importance of sibling involvement. When answering the question, “how old were you when you found out your sibling had ASD”, most siblings could not identify a specific age and also said they did not have a clear understanding of what ASD meant. Participant 6 said, “yes, so I think I was around 6. Yeah, so like 6 years old-ish. I would tell people that he had autism, but I think I would just kind of view him as being different. Not really fully understanding what it was essentially at the time.” Participant 3 answered by saying,

He was probably 2 so that would make me...I don't know 8 maybe, I believe, if I am 21, I think that's right. But I didn't understand what it meant for the longest time... and I didn't understand that all these therapies and like these extra things in our house, like all the sensory items were normal and then I finally understood like in middle school when we kinda like started learning it in school.

Due to the lived experiences participants discussed while growing up in a household with an ASD individual (i.e., communication, stress, support systems, feelings, and responsibility), siblings gave insight on how they felt professionals could help. The participant responses were as follows:

- “I would say making sure the kids understand what is going on with their sibling first...focusing more on what is going on with the sibling. This is especially needed for younger siblings, so professionals can understand better how it is affecting them because it is a lot to see at a younger age.”
(Participant 1)
- “I would say helping...while I think the focus on therapies with the person with autism is very important, there probably also needs to be some like thoughts towards how they can help parents deal with difficulties because I think therapists tend to be very well equipped in terms of strategies but may not necessarily give those same strategies or like communicate those to parents.” (Participant 2)
- “I'd say to just recognize that we know a lot more than it seems like we do. I think especially relevant in like medical situations. I know there's like laws surrounding that and everything but I think it's important for siblings to be involved and aware of that kind of stuff. I mean, especially because if anything happens to my mom, like my brother is my responsibility and I need to know what that looks like. And so, I think involving siblings should happen more.” (Participant 3)
- “Support my parents. Don't make them fight for everything. You know, believe them when they say they need something. Don't make families fight and be exhausted and drained for services that they need so that they can support the rest of their family. So that they can go to work. So, they can be

there for all their kids. So, they can have peace of mind that their child is going to be okay. Don't make them fight for inclusion. Don't make them fight for therapies. Don't make them fight, you know... just support the parents! Yeah. Give them what they need." (Participant 4)

- "Just to have a lot of patience. It can get overwhelming for you too...especially like when they get overwhelmed and they are having a hard day. Sometimes there's just like nothing that can fix it but just time for them to cool down and to regulate themselves. So, a lot of patience that goes a long way." (Participant 5)
- "I wish professionals would look at the impact that this has on the family, siblings, me...Watching holes in walls, head banging, parents just to figure out what day it is, is just hard. I saw everything, my siblings saw everything. It was a lot and I wish any professional would know that it is a lot and we need help too in trying to understand what is happening." (Participant 6)

Prior researchers have examined ASD siblings who participated in support groups and they reported less improvement in their relationship with their ASD sibling (Granat et al., 2012). However, based on participant responses in my study, siblings are asking for professionals to help with more parental and sibling support, specifically with communication, parental stress, and sibling stress. Sibling support groups of children with a variety of medical or mental health impairments, have shown improvements in sibling relationships (Mchale et al., 2012; Zucker et al., 2021). There should be more open discussions, specifically for siblings to be able to express their emotional, mental

health, or physical needs (Connell et al., 2016; Zucker et al., 2021) in growing up with a sibling with ASD. I acknowledge that there are discrepant findings based on prior research and what participants are asking for in my study, however, there should be more research to see if sibling and parental support would be beneficial to siblings who are growing up in a household with an individual with ASD.

Summary

The goal of Chapter 4 provided the study's findings and demonstrate how the methodology was followed. A detailed explanation of the setting, demographics, data collection, data analysis, evidence of trustworthiness, and results, were given. A phenomenological methodology approach was used to understand individual's perceptions in living in a household with an ASD sibling. All participants contributed to this study by giving their personal experiences of what it was like growing up in a household with an ASD sibling. In Chapter 5, I provide an interpretation of the findings and give any recommendations for further research that are grounded in the strengths and limitations of my study.

Chapter 5: Discussion, Conclusion, and Recommendations

Introduction

The purpose of this phenomenological qualitative study was to explore siblings' lived experiences growing up in a household with a sibling with ASD from a retrospective perspective. I sought to speak directly to individuals who had grown up in a family where one of their siblings was diagnosed with ASD about their lived experiences. I wanted to gain a better understanding of this issue from their perspective. The knowledge from the study may enable professionals to assist with early therapeutic interventions between siblings if any sibling crisis situations may arise. Data analysis yielded five themes that encompassed participants' lived experience of growing up in a household with a sibling with ASD: agreement that communication is a barrier (Theme 1); communication issues, behaviors, and sibling stress due to basic needs not being met (Theme 2); lack of support from professionals (Theme 3); the impact of feelings on the sibling relationship (Theme 4); and too much responsibility and feelings of growing up early (Theme 5). Participants expressed a desire for professionals to offer more parental and sibling support, specifically related to communication, stress, support systems, feelings, and responsibility.

Interpretation of the Findings

My goals in conducting this study were to explore the firsthand experiences of individuals who were raised in a household with a sibling with ASD, to identify emergent themes, and to provide information for professionals to improve interventions for individuals who have a sibling with ASD. Upon reviewing the literature, it was evident

that more research was needed to better understand the real-life stories and experiences of individuals who grew up in a household with an ASD sibling. Currently, young adults' perspectives, ranging in age from 18 to 25, are lacking in the research, based on my review of the literature. My findings reinforce how important it is to hear from siblings. The six participants were able to provide insight into what it was actually like growing up in a household with a sibling who had been diagnosed with ASD. They spoke of the professional involvement they hoped to have had during their upbringing. Each participant wanted more support and/or help.

The conceptual framework for this study was the SESF. To incorporate the SESF framework in a way that allows for an understanding of the impact of ASD on sibling relationships, professionals need to hear directly from siblings. SESF is a recommended therapeutic option that encompasses the whole family (Connell et al., 2016; Kovshoff et al., 2017; Zucker et al. 2021). Participant 6 said,

I wish professionals would look at the impact that this has on the family, siblings, me ... Watching holes in walls, head banging, parents just to figure out what day it is, is just hard. I saw everything, my siblings saw everything. It was a lot, and I wish any professional would know that it is a lot and we need help too in trying to understand what is happening.

These shared experiences can clarify resources and assist professionals in implementing appropriate family supports (Kovshoff et al., 2011). Parents can also use supportive strategies to help support healthy relationships with siblings of individuals with ASD (Wheeler, 2019). Participant 2 said,

I would say helping ... while I think the focus on therapies with the person with autism is very important, there probably also needs to be some like thoughts towards how they can help parents deal with difficulties because I think therapists tend to be very well equipped in terms of strategies but may not necessarily give those same strategies or like communicate those to parents.

Prior researchers who have used the SESF approach to examine ASD siblings have drawn participants from support groups. The participants in these studies have reported less improvement in their relationship with their ASD sibling (Granat et al., 2012; Mchale et al. 2012, Zucker et al., 2021). However, based on participant responses in my study, siblings are asking for professionals to help with more parental and sibling support, specifically with communication, parental stress, and sibling stress. Sibling support groups of children with a variety of medical or mental health impairments, have shown improvements in sibling relationships (Mchale et al., 2012; Zucker et al., 2021). There should be more open discussions, specifically for siblings to be able to express their emotional, mental health, or physical needs (Connell et al., 2016; Zucker et al., 2021) in growing up with a sibling with ASD. There should be more research to see if sibling and parental support would be beneficial to siblings who are growing up in a household with an individual with ASD.

Limitations of the Study

There were a few limitations for my research. First, an epoché approach was used when conducting this study due to my professional background and experiences (Zahvi, 2019). Epoché meant conducting research without any pre-stereotypes or biases (Zahvi,

2019). As a licensed social worker, I have a professional background with mental health and therapeutic services. My major client base includes persons diagnosed with Autism and their families. These individuals have expressed the need for professionals to start intervening with siblings sooner versus later. I wanted to find ways to improve sibling dynamics, but made sure my population of interest did not interfere with the data collection. For instance, I had a neutral affect when speaking to participants. I did not want individuals to sense my passion, which could skew their answers.

The interviews were conducted via Zoom. Therefore, I was only able to interview people who had access to an electronic device (i.e., computer, iPhone, etc.) and the internet. This is a limitation because there are issues associated with electronic devices, such as call connection and audio/video reliability and quality (Archibald et al., 2019). During one of my interviews, there were some internet connection issues that arose. The internet froze a couple of times, so there were some delays and requests for the participant to repeat their answer to ensure that I recorded everything. Third, the participants were limited to volunteers. Therefore, this study's findings cannot be generalized beyond the participants (Howlett, 2021).

Recommendations

The interviews were conducted via Zoom. There is a possibility that results could have been different if the interviews were conducted in-person. Krouwel et al. (2019) compared Skype (videoconferencing) and in-person interviews. They found that both interview methods produced a similar number of words and similar number of codes, however, the number of statements with a variety of topics, was notably larger for

the in-person interview. In future studies, I would recommend having an option of an in-person interview, or a Zoom interview. In person interviews could feel more personable, depending on the person (Lindsay, 2016). Lindsay (2016) found that in person conversations had a higher percentage of interview questions asked and more probing questions. Therefore, further research is recommended to see if more details and data can be collected to help professionals increase their understanding on how to best support siblings of individuals with ASD.

In addition to the recommendation for in-person interviews, I would also recommend a different method of recruitment and retainment. Recruitment and retainment are key components in research (Negrin et al., 2022) and can influence the trustworthiness of qualitative research (Krouwel et al., 2019; Lindsay, 2016). In my study, the recruitment process took 8 months. During this 8-month recruitment process, one participant was not retained. In this situation, retainment is defined as when the participant withdraws consent to the study (Desai, 2020). It is possible that the lapse time in the recruitment rate process and the retainment could have been different if incentives were offered (Desai, 2020; Negrin et al., 2022). Further research is recommended to see if there is a different outcome with my study if incentives were used.

Implications

My research findings showed that siblings are asking for help in how to understand, communicate, and interact with their ASD sibling. They also expressed the many different emotions that they encountered while growing up in a household with an ASD sibling. All six participants had advice for professional involvement and services

they wished they had while growing up in a household with a sibling with ASD. “A lot of patience goes a long way” (Participant 5) and “I think involving siblings should happen more.” (Participant 3) Research shows that non-autistic siblings of autistic individuals experienced decreased psychological well-being, less perceived social support, increased aggressiveness and conflict-proness, and higher levels of anxiety and stress impacting their quality of life (Quatrosi et al., 2023). The financial demand, ability to access resources, and psychological challenges in having a child with ASD significantly impacts the mental, physical, and emotional stability of the parent, and any siblings, increasing their risk for depression and stress (Fox et al., 2023).

In my study, participants are asking for professionals to recognize and address the social determinants of health and how it impacts the ASD individual, but also the parents and siblings. Social determinants of health (SOH) refer to any nonmedical factors that influence health outcomes. They are conditions in which people grow, are born in to, or live in, which shapes their life (Fox et al., 2023; Quatrosi et al., 2023). In my research, though the siblings were not the individuals who were diagnosed with ASD, just growing up in a household with an individual ASD, had major SOH, which included communication issues, stress, various feelings, access to support systems, and increased responsibilities. In addressing these challenges, early professional involvement can improve sibling relationships with healthier outcomes and a better quality of life of children with ASD, and their siblings.

Social change is needed with professionals. The goal is to help them better understand sibling interactions, their relationships, and experiences with one another.

This methodological approach is called the SESF. Kovshoff et al. (2017) developed the SESF to explain factors that affect sibling adjustment and to develop clinically, educationally, and empirically based work to enhance and support sibling adjustment, relationships, and well-being in families of children with autism. This framework is not specific to disability research, but is specific to the context of understanding siblings of children with autism (Kovshoff et al., 2017).

SESF is a recommended therapeutic option that encompasses the whole family (Connell et al., 2016; Kovshoff et al., 2017; Zucker et al. 2021). Participant 6 said,

I wish professionals would look at the impact that this has on the family, siblings, me... Watching holes in walls, head banging, parents just to figure out what day it is, is just hard. I saw everything, my siblings saw everything. It was a lot and I wish any professional would know that it is a lot and we need help too in trying to understand what is happening.

These shared experiences can provide resources and assist in implementing appropriate family supports (Kovshoff et al., 2011). Parents can also use supportive strategies to help support healthy relationships with siblings of individuals with ASD (Wheeler, 2019). Participant 2 said,

I would say helping... while I think the focus on therapies with the person with autism is very important, there probably also needs to be some like thoughts towards how they can help parents deal with difficulties because I think therapists tend to be very well equipped in terms of strategies but may not necessarily give those same strategies or like communicate those to parents.

SESF involve support groups, resources, and strategies that are specific to siblings of individuals with ASD. These resources would include communication, education awareness, one-on-one time, interactive skills, safety in the environment, expression of feelings (Wheeler, 2019; Zucker et al., 2021), and an opportunity to have a normal life (Wheeler, 2019). In my study, these resources are what all six participants were asking for. The positive social change for SESF is that it is a resource to siblings when addressing living experiences in a household with an individual with ASD. The SESF approach would help address all of the emotions (i.e., fear, scared, etc.) and experiences that siblings mentioned in my study. Siblings with more positive supports are likely to interact in a better way with the sibling with autism versus if there were more stress factors (Kovshoff et al., 2017; Newman & Newman, 2020).

Conclusion

In conclusion, research suggested that professionals should take a *family centered* approach when addressing ASD siblings since interrelationships are very important (Kovshoff et al., 2017; Petalas et al., 2012), also known as the SESF approach. My study investigated young adults and their retrospective perspective on growing up in a household with an ASD sibling. Interviewing ASD siblings was the most beneficial way to shed light on their own experiences and concerns that ASD has had on their adult life (Chan, 2016). In this study, siblings have expressed being scared and/or fearful through their childhood experiences in being raised with a sibling with ASD. Siblings are asking for increased communication and interactions with their sibling diagnosed with ASD. SESF focuses on understanding siblings' experiences and how these experiences impact

their relationships with different family members (Kovshoff et al. 2017). SESF is an effort to help improve sibling dynamics, relationships, but overall, the well-being of all children who live in a household with an ASD person (Kovshoff et al., 2017). This understanding can be beneficial for professionals and the social change that is needed to assist with early therapeutic interventions between ASD siblings.

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Appendix A: Recruitment Flyer

Zoom interview: I am seeking participants who have siblings with Autism

There is a new study called “*Lived Experiences of Siblings Raised with a Sibling with Autism*”, which could help mental health care professionals like therapists and counselors better understand the psychosocial impact of children with autism spectrum disorder on siblings. For this study, you are invited to describe your experiences with your ASD sibling and how it has impacted you as an adult.

This survey is part of the doctoral study for Lamika Thomas, a Ph.D. student at Walden University.

About the study:

- One 60-90 minutes online interview
- Zoom interview, which will be recorded

Volunteers must meet these requirements:

- 18-25 years old
- Have a sibling who has been diagnosed with autism
- Currently, not living at home with parents or parental figures
- Read, speak, and understand English

To respond to this post, please contact Lamika Winfree at [telephone number redacted], or email [address redacted].

Appendix B: Prescreening Questions

1. What is your first name?
2. How old are you?
3. Did you grow up in a household with a sibling who was diagnosed with autism spectrum disorder?
4. Did you grow up in a one or two parent household?
5. Do you currently still live at home or with the ASD sibling?

Appendix C: Interview Questions

1. How many siblings do you have?
2. Where do you fit in birth order with your siblings?
3. Thinking back to your childhood, how would you describe a typical day with you and your siblings?
4. Tell me some childhood memories that stand out with you and your sibling with ASD?
5. How old were you when you found out that your sibling had ASD?
6. What was your understanding of what autism was when your sibling was diagnosed?
7. How has that understanding changed over the years?
8. What was it like growing up in a household with a sibling with autism?
9. What would you wish your parents would have known about what it was like for you when you were growing up in relation to living with a sibling with autism?
10. If you had to give any advice to professionals about growing up in a household with an ASD sibling, what would it be?

Note: Further questions will be asked based off responses to questions.

Appendix D: Human Subjects Training Certificate



Completion Date 18-Mar-2022
 Expiration Date N/A
 Record ID 48024308

This is to certify that:

Lamika Thomas

Has completed the following CITI Program course:

Not valid for renewal of
 certification through CME.

Student's
 (Curriculum Group)
Doctoral Student Researchers
 (Course Learner Group)
1 - Basic Course
 (Stage)

Under requirements set by:

Walden University

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